Digital Arts Based Research Methods
For Teenage and Young Adult (TYA) Cancer Patients

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Declaration

I declare that the work presented in this thesis is my own. Reference to the work of others has been cited and indicated throughout.

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Abstract

In recent years there have been a number of reviews of art therapy and arts in health research which have mainly targeted interventions that make use of traditional visual art media such as drawing, painting, clay sculpting and the performing arts with little acknowledgement of digital visual arts exploration. This research helps to address this evidence gap, and to build a more rigorously evidenced argument, by examining the therapeutic and wellbeing outcomes of engaging with digital visual art media.

This undertaking is realised through using digital art-based research methods. This project is unique in that it was given NHS R&D approval to work with Teenage and Young Adult (TYA) cancer patients in the ambulatory day care unit at Macmillan Cancer Centre University College Hospital London. This took place shortly after its opening in 2012, therefore, it is the first study of its kind in this hospital.

Mixed methods digital and traditional art co-design workshops were held weekly for two years and nine months, with a total of 120 TYA participants. The visual art data produced in the workshops and observational journals are examined for wellbeing indicators.

The data from the initial iteration of activities suggests that indicators such as achievement, increased optimism and being active are produced through activities in which the participant works individually. The closing activity, in which up to six TYAs participated in a collaborative body map, generated additional outcomes, resulting in the appearance of indicators such as respect, feeling safe, and inclusion.

In conclusion, the practice of mixed methods research can yield differing yet complementary evidence. TYA participation in the design process was key in identifying features that point out wellbeing benefits that could lead to a research-based prototype.

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Personal Motivation

My memories of Silicon Valley in the 1980s are strange and colourful, the hot summers seemingly lasting forever. My mother worked long hours in the semiconductor industry as a manager overseeing the manufacturing process of integrated circuits. Often, I would find myself surrounded by her software engineer colleagues talking tech at our dinner table during the holidays. In 1982, my mum bought me an Atari game console, additional childcare for the working mother. I loved playing Space Invaders and Pac-Man for hours at a time. In 1981 MTV became the official pioneer of the experimental genre of mini-movies that became music videos.

The combination of playing video games and watching MTV was the very beginning of my digital media-based multi-disciplinary art practice. The non-linear narrative structure and the collaged imagery of the early MTV videos made an impression on me and formed a part of my identity. I can say the same of the digital medium of the Atari video games that felt primitive somehow and had a modern sophistication all at once. The adjective that describes early vector-based digital media graphics could be 'crunchy', almost as if you can hear it breaking down when moving and shooting through it, similar to when you destroy a piece of polystyrene and it breaks into thousands of tiny little balls.

Digital media for me has a kind of intellectual tactility that I experienced for the first time in the 1980s. New, fresh art forms such as video games and music videos were outlets, in addition to my drawing practice. I speculate now that it was a form of therapy for the confusion and bewilderment that I experienced coming of age in a fast-paced technopole like Silicon Valley. Having the academic pressure of growing up in the shadow of Stanford University, combined with the inherited legacy of the psychedelic 1960s and the liberal and progressive ideologies that are stereotypical of the San Francisco Bay area even today posed particular challenges for me and my peers. As the character Judge on the TV sitcom *Silicon Valley* suggests, 'It's capitalism shrouded in the fake hippie rhetoric of "We're making the world a better place," because it's uncool to just say "Hey, we're crushing it and making money"' (Marantz, 2016).

Bay Area progressive thinking at its best provided the less cynical memory of the interdisciplinary art and science museum Exploratorium, which was founded in 1974. The Exploratorium was a frequent destination for my school field trips starting from Year 1. Art and science experiments based on the interactive tactile displays were woven into classroom

activities. The concept of interdisciplinary studies had been introduced to me at an early age, affecting how I would approach all of my future learning scenarios. The Tactile Dome exhibit, designed in 1971 by Dr August F. Coppola, particularly impressed me. The exhibit is encased in a geodesic dome about the size of a large weather balloon. Visitors enter through a light-lock room into a totally dark maze (path). Then, for an hour and fifteen minutes, they feel, bump, slide and crawl through and past hundreds of materials and shapes which blend, change and contrast (Exploratorium, 1971). The Exploratorium was an important Bay Area cultural force in my early developmental process.

This learning within an atmosphere of experiential arts and science influenced my way of thinking to find the connection between therapy and digital arts, motivating me to do my research and investigate the health and wellbeing benefits of digital media and to create art therapeutic prototypes of my own that you will find in the following chapters.

As a multi-disciplinary artist working in digital media, traditional art forms and collaborative processes, I began my arts academic journey studying painting and obtaining a BFA from the San Francisco Art Institute (SFAI) in 1998. During my stay at SFAI, in addition to my painting classes I took a performance art class in the New Genres Department. New Genres was initially a performance art and video course that quickly began to encompass social practice and other trans-disciplinary media approaches in which responding to society and culture are highly encouraged (SFAI, 2017).

After graduation I went on to teach myself digital animation, Adobe Photoshop and Adobe Illustrator and found that I could blend these programmes with my drawing and painting practice. Through being an active member of the San Francisco arts community, I was fortunate enough to exhibit my work at venues such as the Museum of Modern Art, Yerba Buena Center for the Arts, S.F. Arts Commission Gallery and Southern Exposure. With the help of these credentials I went on to teach new media and digital animation in Mountain View, California at the Community School of Music and Art (CSMA) from 2006–2009. It was in this role that I began to observe the health and wellbeing benefits of digital animation ‘This process fosters self-efficacy, empowerment, and clearer perspective’ (Garner [ed.], 2017, p. 18). I created the content for the curriculum from my direct experience of making fine art with digital art programmes. I experimented with the students making abstract auto-portraits and publishing their own multi-media zines.

In the summer of 2008, I was invited by the Citizens of Europe to participate in an artist residency in Serbia funded by the Swiss artist fund. The residency had an

interdisciplinary approach of inviting anthropologists and ethnographers from the University of Belgrade and international artists to engage in artistic interventions with the community. It was in the town of Požarevac that I first used digital media consciously in a therapeutic way. I downloaded free software on to the computers in the local internet café and advertised free digital animation workshops. The participants were a small group of local young boys playing violent gun-based video games, some of them refugees from Kosovo suffering from post-traumatic stress disorder due to the war in 1998–1999. I began to see that offering them an option to express themselves with digital media in creative ways again had the same health and wellbeing effects that I had observed in my digital art classes at CSMA. I named my project 'Creation vs. Destruction' to describe the militating relationship between the two options of creating and destroying.

With my familiarity with digital media and a desire to know more and advance in the field and in my teaching career, I successfully pursued an MA in Digital Media, Technology and Cultural form in the Media and Communications Department at Goldsmiths, University of London. After completion of my MA I had the opportunity to research with Professor of Visual Arts and Research Janis Jefferies, Professor of Computer Science and Pro Warden (International) Mark d'Inverno and Professor of Creative Computing Mick Grierson on the Arts and Computational Technology PhD programme in the computing department at Goldsmiths. Janis, Mark and Mick became my supervisors, and this is when my research journey into the health and wellbeing benefits of digital arts media began.

Chapter 1: Introduction

I am an artist-researcher and principal investigator uniquely positioned in the clinical hospital environment. In this study I synthesize inventive and unexampled contributions to the arts in the health sector, therapeutic arts, art communities and research communities. I do this through the development of digital arts-based research methods for cancer patients who are teenagers and young adults (TYA) (ages 14–24). The key research question is: What are the precise health and wellbeing benefits of using digital arts-based research methods with TYA cancer patients.

Using these methods, I sought to generate and document a body of digital visual art data created by TYA participants. This data takes the form of digital images, videos, animation stills and observational journals. The aim of this research is to provide insights for the design of a digital art therapeutic software prototype based on evidence of the TYA's interaction with digital art media.

This research placement took place in the University College London Hospital Macmillan Cancer Centre in 'The Hub' with the TYA cancer patients in ambulatory care. The main study period was 2013 – 2015, with another study period in 2017, and it included 120 participants. I had the experience of undertaking several different duties at UCLH beginning in March 2013, with a role as a creative volunteer, then temping as a youth support co-ordinator for three months, and finally an externally hosted Goldsmiths arts-based researcher at UCLH with NHS Research and Development (R&D) approval, which I received 2015. These different roles have enabled me to conduct research side by side with nurses, doctors, psychotherapists, sound therapists, play specialists and occupational therapists. In doing so I gained in-depth knowledge, from multiple perspectives, of the many different cancer treatments that patients undergo.

I was drawn to work with TYA cancer patients because they are coming of age in an era where everyday lives are technologically mediated with an unprecedented degree of intimacy and intrusion (Braidotti, 2013, p. 89). It is important to acknowledge that this is the case in a city such as London, although not in other parts of the non-western world for economic reasons and also by choice. Some TYAs live their day-to-day lives with and through alternate forms of digital media. A national survey by the Kaiser Family Foundation conducted 10 years ago found that 8- to 18-year-olds devote an average of seven hours and 38 minutes to using entertainment media in a typical day (more than 53 hours a week)

(Kaiser Family Foundation, 2010). In addition, the voice of this age group has great value because of the effect of technology on their investments in image, identity and aesthetics as well as the destabilising aspects of physiological changes all happening to them simultaneously.

With this study group I undertook digital arts-based research through the design and facilitation of digital animation and digital arts workshops engaging with multi-disciplinary approaches. In these workshops I mobilised a co-design methodology in which the main features are participation and collaboration while designing with, and not only for, participants. This allows the patient's voice to have agency to guide the project. I used existing graphics arts software as evaluative tools for observation of the participants while facilitating the production of the art artefacts for visual ethnography. Equally, I offered traditional art media in order to design and explore speculative prototypes with the patients. In the workshops I became aware of the limitations of the digital art programmes available to the public. I found existing programmes to be lacking in artistic sensitivity and an aesthetic that engenders an intuitive therapeutic experience. It became the aim of my research to occupy this void by doing the research for the development of an artist-designed art therapeutic prototype using bespoke technology.

Arts in health research indicates that participation in fine arts interventions can promote health and wellbeing and even act as an adjuvant to cancer treatments. Dr Rosalia Staricoff's medical literature review in 2004 cites 385 papers that explicitly link the benefits of the arts to a wide range of health and wellbeing outcomes. This was one of the first robust studies of its kind. However, there are no studies included in this report on the health and wellbeing benefits of engagement with digital animation and digital arts in the arts in health sector. This evidence gap still exists over a decade on, as indicated by several other reviews that have since been published (Fraser & al Sayah, 2011; Clift, 2012; Stuckey & Nodel, 2010; Kelly et al. 2015).

Currently, evidencing the need for this research, art therapist Rick Garner states that there is a 'dearth of art therapy research publications regarding technology use'. That was another indicator that DAT (digital art therapy) is only in its infancy (Garner [ed.], 2017, p. 15). It is within this unique track of study that I position my research and pursue answers to the questions that can be found within this thesis.

This thesis contains research that began in 2011 with a maternity break between 2015-2017 then resumed until completion in 2019. The literature review reflects this and a progression in research is evident throughout the thesis until reaching the conclusion.

Research questions

I formulated many questions before my research began, and many more arose during it and after I had completed collecting data from the workshops. It is the aim of this research that it will continue to formulate questions in the mind of the reader and lead to future research that furthers the concepts contained within this thesis. Here you will find some of the questions that I investigate and respond to.

The key research question is: What are the precise health and wellbeing benefits of using digital arts-based research methods with teenage and young adult (TYA) cancer patients.

The secondary research questions are:

- What does this data tell us about the ways that we can evidence that digital animation and digital arts promote health and wellbeing?
- How can patients participate in the codesign of an art therapeutic app using digital arts-based research methods?
- How can artists contribute to software design for the therapeutic setting?
- How can the relationship between art therapists and digital art technologies be challenged?
- How do digital software and/or devices designed by artists differ from the mainstream?
- In what ways can practice-based research in the digital arts contribute to more effective relationships between art therapists, technology, hospital management, healthcare workers and patients?

Contributions

This interdisciplinary study makes its contribution to the field of Digital Art Therapy (DAT). DAT can be defined as 'all forms of technology-based media, including digital collage, illustrations, films and photography that are used by therapists to assist clients in creating art as part of the process of therapy' (Malchiodi, 2011 p. 33). My practice explores this new territory as outlined by Garner 2017 and Malchioldi 2018. This study focuses on the use of

digital art media for self-expression, not on the influence of digital communication and social networking/social media on the field of DAT and therapeutic practice.

I present evidence in support of the argument that artists should be involved in the process of developing ways for patients to interact and make art with digital media, as this leads to the creation of bespoke art-based research working methods for art therapists and arts in health workers using DAT. The provision and development of greater case study data and evidence in support of this approach is a primary contribution of my research. In support of that contribution, Kelly et al. (2015) conclude in their review of art therapy research, that the way forward for future studies in this area is for "arts therapy researchers to work more closely with researchers from 'purely' arts disciplines (e.g. English, Art History, Fine Art departments) in order to establish what effect arts engagement might be having…For example, this could mean digital artists teaching art therapists how to use existing software and how to choose the best software for their clients' needs" (2015 p. 17).

As Garner, in his work on DAT (2017) states, 'DAT is an area of study that is beyond the traditional realms of art therapy and may possibly become a unique track of study within academic programmes that educate art therapists' (2017 p. 10). Art therapists can benefit more from working together with digital artists to design customised curricula based on their own therapeutic methods with specific client groups. Art therapists stand to enlarge their repertoire of art-making tools, giving them new methods of working in addition to traditional art media to create within their practice.

Art therapists, through the adoption of digital media in their practices, will be better able to reach TYAs during the challenging period of so much physiological, emotional and social development. With increased awareness and knowledge of the impact of digital arts on health and wellbeing, art therapists can prescribe specific digital art therapeutic treatments for different client needs.

My work can be understood and contextualised alongside similar published art therapy research about the therapeutic aspects of digital media (Ancliff, L., 2019; Barbee, 2002; Bucciarelli, A., 2019; Hartwich & Brandecker, 1997; Hoit, J., Jamerson, J.L., 2019; Carroll-Haskins, K., 2019; Chen, A.T., 2018; Dougherty, A., 2019; DICATS, 2019; Fattori,, I., 2019; Horovitz, 1999; Koen, A., 2019; Lohrius, J., 2019; Martin, 1997; McLeod, 1999; Orr, 2005; Parker-Bell, 1999, 2019; Rutherford, 2001; Seiden, 2001; Shu Ning, P., 2019; Soh, E., 2019; Thong, 2008; Wolf, 2007; Wood, M., 2019 b&c; as well as research about what was

found not to be therapeutic (Williams et al., 1997); and the social implications of social media (Belkofer & McNutt, 2011; Kapitan, 2007; Orr, 2011a; 2011 b; 2011c.).

My contribution as an artist enriches research in this field by using mixed methods research approaches with the TYA's at the UCLH MacMillan cancer centre to inform the design of a novel digital art therapeutic prototype. I collected data in the form of digital and traditional art artefacts including narrative analysis that focuses on the stories and accounts from the TYA participants in the co-design workshops. Using an iterative design process and continual analysis of the research data, I have merged the body mapping storytelling method with a digital art prototype. These research activities extend the field of DAT by using existing digital arts applications for the design of a digital art therapeutic software prototype that applies the research with the TYAs that is then integrated within the user experience.

User groups

TYA cancer community

TYA patients are the primary group that my study pertains to. While leading workshops at the hospital I found that there were many people surrounding the patients who benefited from participating in this research, for example parents, carers, siblings and extended family members. I also included the administrative staff, nursing staff and the medical teams that interfaced with the patients and TYA cancer researchers.

Having an art professional embedded in the clinical environment can give additional support to the essential procedures and activities that a cancer patient experiences during a hospital stay. Introducing digital art into the hospital culture encourages a new dimension of self-care that is available to patients. My workshops served to provide a meaningful distraction to this community that gave them an option to focus on a different way of viewing their medical circumstances and to communicate in a visual language. Working in a community of vulnerable people requires empathy, care and best practice in terms of research. I was inspired to deepen my understanding of these requirements and to demonstrate them with the TYA's. Through having the privilege to work within this community for several years, I cultivated creative means of interacting with the patients and communicating with them in ways that helped them to feel comfortable with my research. This study is unique in the field of arts-based research in that there is no other study like it

registered with the Joint Research Office (JRO) University College London Archives (UCL, 2017) available for researchers and students to access.

Play specialists and occupational therapists

Within the hospital setting, digital arts research is of value to play specialists, who organise art activities for patients to help them through their ambulatory or extended-stay visits. While doing my research at UCLH at the TYA Cancer Trust, I worked closely with play specialists and occupational therapists, who directed patients to my workshops. Digital art for self-expression was new to the therapists on the ward. They had not worked with visual digital art practices until I had installed art software on the computers. I offered the therapists an alternative to their traditional prescriptions for pain distraction and the recovery of fine motor skills.

Digital art is also a way for patients to acquire essential technology skills that can enhance their sense of autonomy and experience of play. I felt a close connection to the play specialists while working alongside them; their work is not dissimilar to the arts discipline of social practice that I describe in the following sections. In both fields, practitioners work within the context of a community to bring about positive change, finding tools for the people in the community to problem-solve and provide support from within, aiming to uncover innovative ways leading to self-sufficiency. Mental health professionals have observed that play is as important to human happiness and wellbeing as love and work (Schaefer, 1993). Landreth and Russ also have the following to say on the topic of play

> Play is the child's language, play is a fun, enjoyable activity that elevates our spirits and brightens our outlook on life. It expands self-expression, self-knowledge, self-actualization and self-efficacy. Play relieves feelings of stress and boredom, connects us to people in a positive way, stimulates creative thinking and exploration, regulates our emotions, and boosts our ego. (Landreth, 2002)
>
> In addition, play allows us to practice skills and roles needed for survival. Learning and development are best fostered through play (Russ, 2004).

Research context

Volunteering and building trust

I began my research journey as a creative volunteer at UCLH Macmillan Cancer Centre. This is how I was first introduced to my study group. I was fortunate to be able to work with TYA

cancer patients. To become a volunteer with vulnerable people it is necessary to do an enhanced Disclosure and Barring Service (DBS) check and to be trained in health and safety protocols in accordance with the NHS. On the TYA ward, there is a cluster of eight computers that were donated by Arsenal Football Club. Using these computers, I began by offering weekly animation and digital art workshops with free software. I produced posters to alert the patients to when the workshops were taking place (see appendix). Pg?

I was the only volunteer working with digital arts media with the patients, and this posed different kinds of challenges for working with the patients and giving them the opportunity to exhibit their work. For example, the digital files of their artworks were not accessible without the computer. The ward did not have a printer available for us to use and ink can be costly when printing large colour files. There was not a monitor available to publicly display the animations that the patients made during the sessions. The drawings that the patients made were to be kept for visual data for my research and I did not want them to be damaged while on display. I could only work with patients who were mobile enough to come to sit down at the computers in the communal space. I did not have access to digital tablets to use at the bedside, though I was able to work with patients using watercolour pens, graphite pencils and paper instead.

My supervisor, Annika, was the ward play specialist, and she helped me to interact with the patients to earn their trust and thereby find participants for my study. When she saw that the workshops were a positive addition to patient life, she purchased Adobe Flash animation and Photoshop software for the computers. Having the software always available to the patients contributed to a sustainable digital art culture in the hospital. The availability of the digital arts resources and the self-sufficiency that the TYAs learned in using the software contributed to a type of digital art self-care.

Through volunteering I was able to interact and forge relationships with the nursing staff, administrative staff, cleaning staff, play specialist team, occupational therapists, psychotherapists, the patients, their carers and families, and, significantly, the ward sister, Laura Brown. It was through the trust and relationships that I built on the ward that Laura gave me permission to seek the signature of the lead clinician, who could approve my application for ethical clearance from the NHS to register as a student researcher. I volunteered for two years before the R&D approval process was initiated with the JRO University College London Hospitals NHS Foundation Trust.

When Anika, the ward play specialist retired, I was hired to substitute until her position was filled. I enlisted with the hospital's temporary agency Bank and went through rigorous health and safety training to fulfil NHS requirements as detailed in the professional training section below. In the role of substitute play specialist, I organised daily art activities for the patients and continued to lead the digital art and animation workshops. I gained insight into and knowledge of how to interact with the patients through rigorous on-the-job experience. I worked in this temporary role for three months.

Communities

Arts and science practitioner community

The arts and science field is enriched through the unique context of exploring digital arts with TYA cancer patients in the clinical environment in this study. The neuroscientist Andrew Carnie is 'convinced that artists and scientists can be major resources for each other'. Carnie believes that 'art is too important to be left to artists – science is too important to be left to scientists' (Wilson, 2010, p. 68).

The science historian Arthur I. Miller has explored the coincidental connections between modern art and modern physics and shown how the zeitgeist informs the way we express our meanings at particular periods of history (Miller, 1998). The zeitgeist of this technology-saturated age is the appropriate context to do digital art-based research with TYAs because they were born into a culture of digital technology.

This study, with the contribution that it makes to DAT, extends the art-science movement and seeks to align with the pioneering work of British art-science organisations, examples being the London based Arts Catalyst, The Laboratory at the Ruskin School of Drawing and Fine Art at University of Oxford, Bristol-based Interalia, the Medicine, Society and History Division of the Wellcome Trust, and the Gulbenkian Foundation's Two Cultures programme (Ede, 2000, p. 18).

Arts-based researchers

This project serves as an example of interdisciplinary collaborative arts-based research for artists and arts-based researchers interested in doing similar projects in the clinical environment. The use of inventive arts-based methods such as body mapping a visual

autobiographical story-telling method that utilises traditional art media , which I define in Chapter 2, contributes to a growing body of research methods that can be used for reference in projects related to health and wellbeing and clinical studies. For example, the novel Visual Arts Autopsy (VAA) that is based on the psychological autopsy method as implemented in *Lived lives: A Pavee Perspective* (Malone et. al., 2017).

Social practice community

The artworks made by TYA patients in the workshops at the Macmillan Cancer Centre represent artwork that expands and updates the terrain of work within the 'social practice' art genre. 'Social practice artists and producers aim to affect their community and environment in a real (rather than symbolic) way that enables social and political change' (Helguera, 2012, p. 22). 'We spend years in art school, where we are taught to explore ourselves,' Helguera says, 'but social practice is completely about the opposite thing. It's about how to listen. It's remaining engaged with the world in an active way' (Helguera, 2012, p.9).

Finklepearl, Kester and Bishop (2013) define social practice as 'art that's socially engaged, where the social interaction is at some level the art'. My project shares insights into how to work ethically with a vulnerable group in a social practice mode while adhering to best research practice. Artefacts from the research and speculative prototypes impact the art community by bringing practical new knowledge to academic and medical databases about TYA cancer patients, digital art, and health and wellbeing.

In summary of this chapter I have presented the core concepts of digital arts-based research within this study. The research taking place at University College Hospital MacMillan Cancer Centre with 120 Teenage and Young adult participants within the space of 2 years and 9 months from 2013-15 and in 2017. I have introduced the key research question 'What are the precise health and wellbeing benefits of using digital arts-based research methods with teenage and young adult (TYA) cancer patients' as well as secondary research questions. The contributions to the field of digital art therapy DAT are clearly defined. The research context is mapped out including the pertinent user groups and communities that this research has an impact on. In the following chapter existing research literature on digital art practices within the medical and therapeutic fields is reviewed.

Chapter 2: Literature Review

Over the past decade health psychologists have begun to observe how the arts might have a role to play in healing in a variety of modes; for example, to alter unwanted behaviours and thinking patterns, heal emotional injuries and motivate people to understand themselves and others, resulting in the reduction of symptoms (Camic, 2008). This work intersects strongly with my main research questions. This can be employed in art interventions in the arts in health sector, while also being adopted by art therapists using digital art mediums alongside the traditional art mediums that they regularly employ. It is important to make the distinction that art therapy is a treatment based on therapeutic intervention informed by the practice of psychology, psychotherapy and psychiatry (Broderick, 2011) with a set code of ethics and practice run by a professional body. The work undertaken by the wider arts in the health sector is concerned with a wider spectrum of potential benefits, such as social inclusion and the improvement of local communities.

This review charts existing forms of creative expression through digital media as a healing process that has been used in both clinical and informal practice to promote health, wellbeing. In this chapter digital art media, therapy and healthcare was examined through the existing research available. Digital art software is reviewed and the differing views on the adoption of digital art by art therapists is critically taken into account. In the following pages the past present and future of digital art, therapy and healthcare research sets the foundation for this thesis.

Art therapists' emotional reactions to digital media

Art therapist Cathy Malchiodi has been investigating the intersection between art therapy and computer-based and electronic technology for more than two decades. Malchiodi states some of the dilemmas that art therapists face:

> Ironically, art therapy as a field is a slow adopter of new ideas; in a recent special art therapy journal issue on technology, there was no reference to the well-known Project Sketch-up and many of the very common digital and social multimedia advancements. Art therapy has been hesitant to even recognise photography as an important medium in treatment and intervention; art therapists tend to remain loyal to traditions, even when those traditions are not proven to be best practices. Meanwhile, younger generations of potential clientele have grown up on digital and

> social multimedia and are more attuned to them than pencil or paintbrush. (Malchiodi, 2009)

The emergence of computer technology in the field of art therapy roughly parallels the increase in the use of computers by the general public, which is a relatively recent phenomenon of the 1980s and 1990s (Malchiolodi, 1999). This being said, art therapy as a field has been slow to incorporate digital technology into its repertoire of tools and methodologies. This is evident from the worldwide current body of research included in this review. This is related to how art therapists emotionally connect to computers and the digital medium. Kapitan asserted that in order to participate as artists in the techno-digital culture, art therapists must broaden their definitions of art materials and contexts across a wide spectrum. She believes that 'we must be willing to move beyond historically validated media and offer our work in new contexts' (Kapitan, 2007, p. 51). These historically validated media include painting, sculpting, collage and textiles, where the art therapist was likely to be formally trained in at least one. Drawing on data from research performed by Asawa, an art therapist describes her emotional reaction to making art with a computer: 'The overriding experience, was that I felt that the technology was a block to creative expression' (Asawa, 2009 p. 61). She asserted that she was surprised by this reaction because she did not think that she had a fear of computers, given her level of computer literacy, but something was blocking her, nonetheless.

The first published article exploring art therapists' emotional reactions to technology was in 1975, written by psychologist and art therapist Judy Weiser, on the use of photographs in art therapy, now known as photo-therapy, of which she is a pioneer. Interestingly, photography was not readily accepted in art therapeutic circles. It has been reported that our emotional response to technology affects whether we adapt and are motivated to include such digitalism in an art therapeutic activity. 'Emotions influence our lives all the time. They can shape the quality of our relationships and they motivate most of our activities' (Ekman, 2004, quoted in Asawa, 2009 p. 5). 'Because art therapists are also artists, they have personal experience with most media and processes, which is how they become acquainted with such media and help others learn to use them comfortably' (Rubin, 2010, quoted in Peterson, 2010, p. 27). The mediums that artists tend to prefer and find value in, out of necessity, will need to be user-friendly for use in art therapy.

Resistance from art therapists to using digital technology

There are reasons for resistance from art therapists to accept and use technology in their therapeutic practice. Many feel that when you use digital technology that it is no longer art. There is fear, lack of confidence, and problems with art and design programmes not being user-friendly enough. The most interesting of these barriers is the therapists' or educators' feelings that technology-based art making is cold, isolating and non-sensory oriented. The results of Penelope Orr's survey targeted at 250 American Art Therapy Association members (AATA), who were either current students or practising art therapists, suggested the distant, non-tactile nature of technology-based art-making tools appear to leave some therapists with doubts about whether it has therapeutic qualities. There is also a sense in the responses that 'traditional' art-making media is more therapeutic than technology-based tools. One therapist stated, "Clients need the sensory elements of traditional art materials for recovery," and another said, "Don't forget the art!" (Orr, 2006, p. 195). The belief that the sensory elements of traditional art materials are somehow superior to digital art media for recovery is highly debatable. Digital media induces its own kind of very palpable sensory characteristics. Barbara Parker-Bell (1999) has written about the possibilities associated with the use of computers for art therapy. Her article considered the notion that computers may be underutilised because many art therapists are not educated in the operation of the computer hardware and software related to graphic design. Harthwhich and Brandecker concluded: 'prejudice against the computer comes more from therapists than from patients' (1997, p. 372). Art therapists may resist the use of digital imaging technology (DIT) more than their clients do (Peterson et al., 2005, p. 140). The world has changed, though art therapists are slow adopters of technology and – as I have stated previously – many are reluctant to adapt to these changes.

Furthermore, there is also very little research in the field of arts in health that can provide evidence of digital art media having an effect on health and well-being. Arts in health is covered later in this review. At the moment it is difficult to help art therapy clients have a meaningful relationship with digital media due to problems with the design of the available software programs. To date, according to my research into the literature, there is not a single digital device that is repeatedly and widely used in art therapy sessions or in art interventions. The existing art software programmes are mainly used by art therapists in the USA. Malchiodi recommends the following software, apps, and devices to be used with

hospitalised children in her book *Art Therapy and Health Care*:

> for drawing, painting and collage software – Artweaver, Tux Paint, Art Rage, Dogwaffle, Gimp, Picassohead, Apps – SpinArt and SpinArt Studio, Uzu, Art of Glow, Thicket, Meritum Paint, Pottery HD, Drawing Pad, Photowall, Helloflower, and Communitas (Malchiodi, 2013, p. 109).

I have not found any current art therapy research in the UK or USA that uses these programs consistently, with the exception of recent research on Project Spectrum, which uses Google SketchUp with children and teenagers who are on the autism spectrum. SketchUp was one of the main programmes used for art therapeutic research at Coventry University, UK, between 2003 and 2006. This research initiative investigated, designed and built a sensory environment for children on the autistic spectrum. The environment explored the use of digital technology to provide sensory stimuli in a fun and engaging way for the children. Based at the Coventry School of Art and Design, the project has forged links with local schools and communities, as well as with fellow researchers and practitioners. Any other research I have found has very limited data and the research uses very simple paint programmes such as in Thong's 2011 article 'Redefining the tools of art therapy'.

This may be because of the poverty of artistic design and intuitiveness in extant art-making software, as well as lack of research in arts in health and in art therapy. Perhaps there has been inadequate consultation with artists and art therapists or none at all. Gussak and Nyce (1999) indicate as much in their suggestion that technology might be underutilised because programmers do not design user-friendly software that corresponds with art therapists' needs. According to Ben (2007), it may also be the case that the software is not user-friendly to art therapists, who tend to be women, because software designers are typically men. As Gussak and Nyce argue, perhaps more women artists are needed to consult and design programmes that can be user-friendly in the art therapeutic and educational environment. Although women work in information technology, they are less often employed in the design and development of software (Ben, 2007). That being said, little has changed since this article was published in 2007. The field of software engineering is changing rapidly and the number of job vacancies in computer science is expected to explode to 1.4 million by 2020, although the US Census Bureau has found that women's representation in tech occupations has actually been on the decline since the 1990s. Asawa reiterates the preceding concerns in her essay about art therapists' emotional reactions to the demands of technology: 'Art therapists are rarely consulted in the process of creating

software designed for the flexibility and intuitive process that they value. This has many nuanced implications for the field of art therapy related to gender and affective responses to technology' (2009, p. 59).

The preceding quotes together with my own observations point to a deficit in deployable digital tools being appropriated and used with any kind of regularity by artists and therapists in the promotion of health and well-being.

Digital media in the practice of art therapy

Pioneers exist in the field of art therapy, having experimented with various new media in therapy treatment, with more attention focused on the computer medium in recent years. Visionary art therapist Diane Weinberg in 1985 addressed the interface of art therapy and computers in one of the first articles written on this topic. Since the client population with which she worked had physical limitations like quadriplegia, brain trauma and stroke, she could see the potential of computer art therapy as a rehabilitative support to conventional art therapy. She also noted the possibilities computers had for monitoring patients' cognitive abilities. For example, because computers have the capability to recognise and remember decisions made about composition, design and colour, they could conceivably be used to record for research purposes how patients use them to make decisions, solve problems and express themselves creatively. Art therapist Devorah Samet Canter first appeared on the art therapy scene in the 1980s, and like Weinberg, was far ahead of the field in her enthusiasm and vision for computers' interface with art therapy. She brought live computer demonstrations to national conferences of the American Art Therapy Association (founded in 1969), later encouraging patients to use graphics software and to participate in electronic communication to establish social support from others beyond their hospital bed. However, there are surprisingly few published articles dealing with the application of new media in art therapy as well as the 'arts in health' sectors in the UK.

It is surprising that the use of digital art media in an art therapeutic context or arts in health interventions is not more widespread, considering that the little existing research that supports the health-promoting benefits of digital art media is so positive. This is true particularly now that people are spending more time on computers and hand-held digital devices than ever before, especially young people. As the world embraces screen culture, a way is required to meet the changing needs of art therapy clients and of participants arts in health interventions. One such proposition is the use of specially designed software and

digital art programmes that encourage expression in a contemporary way that reflects the impact of digital culture.

Returning to Malchiodi's observation cited earlier, she states in another more recent article:

> Honestly, many of my art therapy colleagues who consider themselves to be experts on art media have not yet caught up with the interface of digital tech with arts therapies, social media and communication. But what I do hope they will catch on to is the inevitable cultural rewiring that is taking place due to digital devices, largely the result of Jobs' vision. Our clients are interacting with the world in ways I could not imagine at the start of my career—they are now holding screens in the palm of their hands, measuring their worlds via gigabytes and terabytes rather than inches or millimetres, attuning to touch technology as a method for both communication and creativity, and expecting ubiquitous digital connectivity (Cathy Malchiodi, 2011).

This cultural rewiring due to the frequent use of digital devices is an important factor in driving the necessity for user-friendly digital art therapeutic instruments for clinical use and art interventions.

> Today's youth (particularly teens and young adults) find it difficult to live without newer technologies such as compact discs, graphic-based video games, MP3 players, high-powered computers, cell phones, and digital assistants, some of which were not available even 5 years ago (Orr, 2006, p. 191).

Accepting that these cultural shifts have already happened and will continue to evolve, how can we successfully intercept the attention of clients who are participating in digital society to best serve them therapeutically? One would think that the most efficient and beneficial way to reach them is directly through the media that they spend the most time using, the screen and other digital devices. By spending so much time watching screens, people adapt to a visual culture where learning takes place through the moving image, the image being text, motion graphics, and video. Art therapist Penny Orr asserts that -

> The current generation of students in our society is grounded in visual culture that requires an understanding of technology-based multisensory communication with multiple truths and interpretations (Orr, 2006, p. 191).

Lev Manovich has observed that our younger generations are speaking a different and new language that has been influenced by growing up with new media and digital media platforms. They are speaking the language of computer culture, as explained by Lev Manovich:

> Conversely, if we simply mimic the conventions of older cultural forms such as the printed word and cinema, we will not take advantage of all the new capacities offered by the computer: its flexibility in displaying and manipulating data,

> interactive control by the user, ability to run simulations etc. But there is one thing we can be sure of. We are witnessing the emergence of a new cultural metalanguage, something that will be at least as significant as the printed word and cinema before it (Manovich, 2001, p. 93).

Manovich argues that the language of cultural interfaces is still in its early stages, as was the language of cinema 100 years ago. A comparison can be drawn here about the language of new cultural interfaces being like learning to use digital media for art therapists, and the familiar language of cinema as being understood and accepted as traditional art mediums. For digital media to be widely accepted by art therapists, it will need to be trialled and processed through practice and thereby become understood and assimilated, as with any art medium.

Digital art therapy

The DAT movement has emerged from the previous literature and art therapists who embrace digital art media. Art therapist Rick Garner states that there is a 'dearth of art therapy research publications regarding technology use, indicating that DAT is only in its infancy' (Garner [ed.], 2017, p.15).

Arts in health and art therapy

The issue of the role of artists working in healthcare settings and the role of art therapists requires clarification. There is much discussion about the interrelationships between the two areas of work. It is important to make this distinction because, as an external researcher at UCLH MacMillan Cancer Centre, I am working within the 'arts in health' sector through the initiation of my digital arts workshops.

It is important that the reader understands that I am not an art therapist, but an artist and researcher. There is a difference between art therapists and artists working in a healthcare setting, i.e. arts in health. Art therapists work as part of a medical team and are concerned with using the arts towards a therapeutic outcome. In the participatory arts in health projects such as London Creativity and Wellbeing Week 2014 promoted by the London Arts in Health Forum, the artists' work complements that of the medical team; they are more dedicated to using their skills towards creative output. An example is the 'Painting your Pathway' project that is included in the Creativity and Wellbeing Week, where the only rule in the class is that nobody ever comments about another person's painting; paintings

are never critiqued or analysed. Through the encouragement to express oneself artistically without the weight of analytical evaluation, the activity of making art contributes to health and wellbeing. In this process, creative artefacts are produced which remind the patient of the journey and aid in personal recovery**.**

What is 'arts in health'?

There are two important documents published by the Department of Health (DH) and Arts Council England (ACE) that demonstrate the breadth and depth of this concept: '*Arts in Health' Sector*: *Report of the Review of Arts and Health Working Group* (Arts and Health Working Group 2007) and *A Prospectus for Art and Health* (Arts Council England 2007). These documents draw on evidence such as Dr Rosalia Staricoff's medical literature review, published in 2004. Within the *Report of the Review of Arts and Health Working Group,* the DH made a clear statement in support of the role of the arts in health: 'The arts are and should be firmly recognised as being integral to health, healthcare provision and healthcare environments' (2007, p.3).

There are many different ways in which this work is described (*arts in health, arts for health, arts and health* etc.) but essentially, they are all about the effect that active engagement in the arts can have on the health and well-being of individuals and communities. As work in this area has grown, the understanding and measuring of its impact have also grown, and now there are a number of academics around the country investigating the impact that the arts have on health.

There are numerous people working in arts in health; these include art therapists, researchers and curators who manage arts programmes in hospitals. For example, Guy Noble, who is the arts curator for UCL Hospitals, curates art in hospitals and is involved with the Wellcome Trust and Collection that houses exhibitions and artefacts that are concerned with medicine and healing processes. There are collaborative art projects through UCLH arts and the Camden Art Centre such as 'Radio Writing', where the project commissions an artist to create new work for both hospital radio and live performance. Artist Sarah Tripp created a live performance exploring chimes and the written word at the Camden Art Centre during her 'Radio Writing' residency in April-June 2013. For hospital radio Tripp created a sequence of hourly chimes to evoke the passing of the day. There is a variety of creative volunteers at the MacMillan Cancer Centre who engage patients in various poetry, writing and crafts activities on a weekly basis. In the years leading up to 2020, Guy Noble will be

commissioning new artworks for the hospital's permanent collections. I have interviewed Guy Noble about digital art media and how he views it's place in the hospital (see appendix).

Participatory arts

Getting involved in the arts provides both social and creative outlets for people who are ill, whether with physical or mental health issues. For example, a 2010 study conducted by the Mental Health Foundation found that participatory art programmes provide opportunities for meaningful social contact and support within the art groups themselves as well as improving relationships between those living in care homes and prisons. Many care homes, GP surgeries and hospitals, as well as community settings, provide opportunities for people to engage with the arts as a tool for improving their well-being. I am approaching this research from the perspective of an artist who is invested in the performance, conceptual materiality, and practicality of the digital medium. I am not an art therapist, though I aim to develop collaborative projects and design digital art tools that can be adopted readily by artists, non-artists, medical staff and therapists alike.

I have found that there are many case studies conducted in the arts and health sector that support the view that arts interventions significantly promote health and well-being, while also helping with pain reduction and a general improvement in the atmosphere in the health care environment. These case studies can be found in 'Arts in health: a review of the medical literature' (Staricoff, 2004), which includes an analysis of the effects of different types of traditional art and performative art forms and an overview of the current scientific knowledge on:

- Mechanisms of art perception
- Mechanisms of art processing
- Association of art and emotions

This review, however, does not consider the effects of digital art. Similarly, there are surprisingly few published articles dealing with the application of visual digital media in art therapy in the UK.

Software review

The previous sections have focused on why art therapists have been slow to use digital media in their work. The literature review suggests that the current design of available software programmes does not support art therapy clients to have meaningful experiences. At this juncture, a review of software programmes that are available, though largely neglected, in my experience, will shed some insights into current practices.

There is an app for art therapy, 'Computer Art Therapy', developed by AAA LAB (Artificial Intelligence, Applied Statistics, Art Therapy) at Korea University Seoul. The project is led by Professor Seong-in Kim at Korea University and a team of colleagues and students who are interested in applying technology to art therapy and measuring graphic aspects of drawings. By Western standards, analysing artwork is not technically 'art therapy', which is generally defined as an expressive therapy approach. Most art therapists are interested in understanding the content of their clients' images; some practitioners help clients explore the meaning of their art expressions while others continue to search for ways to evaluate various characteristics of artwork for mental illness, cognitive and developmental disorders, and personality traits. Korean art therapists tend to fall into the latter category and appreciate art therapy as a way to interpret drawings in order to derive symbolic content. Here is what the AAA Lab has to say about their project:

> This app is based on the service that had been formerly made manually by art therapists with the computer-based system, and is composed of free drawing, mandala, and kinetic family drawing services. If a user inputs a free drawing, mandala or kinetic family drawing along with the personal information to the app, the system provides the result of analysis on the drawing as well as psychological and disability status in the output stage. This information stands on the basis of knowledge base built on abundant expertise, experience, and research data on art therapy (AAALab, 2013).

AAALab also says:

> The reason why the utility of evaluation and transparency of an image falls under suspicion is because there is a lack of reliability and consistency between the evaluations from art therapists and a lack of validity in the result of evaluations. We developed C CREATES (Computer Colour, Related, Art, Therapy, Evaluation, System) as one way to solve reliability and validity problems caused by the personal subjective experiences of art therapists (AAALab, 2013).

Apps like this one – if it were to become widely accepted – are what I think art therapists fear about technology: that there is the possibility of an automated art therapy that can outsource their expertise to computer software devices. The anxiety surrounding

the elimination of the human therapist altogether is understandable. There exists this rising concern about technology in general in the health and caring professions that caring robots may replace human caregivers. Turkle (2011) has further debates around the anxieties of robotic healthcare.

Malchiodi, art therapist and digital art therapy pioneer, became a subject in 2012 to test the software in Professor Kim's project via the Computer Art Therapy app; anyone can do the same by downloading the free app and signing up as a member. First, the user will be asked to answer a series of questions about their colour choices (favourite colour, least favourite colour, 'happy' colour and colours that represent themselves, their mother and father) and some basic demographics. The user then completes a drawing of their choice using their choice of virtual crayon, paintbrush or felt marker and submits it to the website for analysis. The analysis takes about five minutes. Malchiodi wrote about her own results:

> When the analysis was complete, I was provided with several charts that listed the colours in my drawing and the percentages of each colour I used. This was followed by an interpretation of my colour usage, presumably based on the colours I used. Here are some of the highlights of the app's analysis:
> **White:** You are likely to be an honest character with a strategic mind. **Blue:** You are considered to be intuitive and self-conscious (as to the latter, only in a bathing suit). You are likely to be a sympathetic person with advanced communication competence (say, those are good attributes in a therapist and a blogger). You seem to have a talent for sales (I guess I missed my true calling in life). I am not sure why, but I did not get much more information than that, even though I used many colours in my drawing and some more blue than white. I did do quite a bit of virtual "erasing" and layering of colours in my iPad drawing; that is my personal painting style and sensory preference for art making when using traditional materials. I also wondered how the meanings of various colours were derived and if they were based on Korean culture or some universal model selected by the researchers (Malchiodi, 2012 online).

Malchiodi's experience with the art therapy app reminded me of the Magic 8 Ball, yes/no oracles and various tarot card readings where you can ask simple questions and get an answer generated by an algorithm. It appears as though the colours that are used trigger a database of specific answers controlled in variations by the percentages of the colours used. This programme could have the potential to cause anxiety rather than relieve symptoms. The pat answers and evaluation of drawings could cancel out any positive feelings that may arise from the guided process-driven artwork. Invariably, the statements are leading and they manipulate the user to think in a particular way rather than having a person-centred humanistic approach where the client is given the freedom to define themselves (Rogers, 1980), although 'defining oneself' is equally problematic (false and

selective memory, witness to oneself as unreliable, providing information that the therapist wishes to hear). Consequently, this app received poor customer reviews on iTunes such as 'poor quality', 'quit unexpectedly', 'waste of time by art therapy grad', 'worst app I have ever downloaded' and 'don't do it terrible app'. A more sophisticated or nuanced iteration of the project by AAALab employs artificial intelligence (AI) by exploring the idea that emotion detection could be imparted to a computer and is similar to the perspective of abstract artist Wassily Kandinski, that abstract artwork is actually emotionally objective in its character. A research team from the University of Trento, led by Nicu Sebe, decided to see if they could prove Kandinsky's theory with regard to computer AI. As it turns out, the computer AI actually predicted expected human emotion inspired by each painting and had an 80 % accuracy rate after those results were matched up with the opinions of 100 participants (Plafke, 2012).

The following software programmes, excluding Effusio, are not specifically designed for therapeutic use, though they are the most widely deployed among artists and art therapists who do use digital technology.

Sketchup

This program is known for its use in Google's Project Spectrum.

> Some individuals with developmental disabilities – autism in particular – may interact more successfully with computers and their associated programmes than with traditional media. Limited social skills that are attributable to their diagnosis may impede dynamic face-to-face interactions; technology makes the attainment of these skills more linear and less time dependent. The program exemplifies the fact that as a user's experience improves, intuitive interactions become the norm. This phenomenon increasingly will allow everyone, regardless of cognitive abilities, to partake in digitally creative activities. For people with developmental disabilities, a wide range of activity is now possible and will continue to expand as technology advances (Beck, 2011).

SketchUp (SketchUp, 2013) has the most positive feedback data collected on it and is the only research project of its kind that appropriates open-source software for the purpose of art therapy. Impressive artefacts created by young people on the autistic spectrum can be found at www.autismcollaborative.org/art/. The most popular feedback about Sketchup is that it is extremely user-friendly. Conceptual artist and colleague Stephanie Syjuco used this software for an exhibition in 2009. This suggests that the programme is a medium that artists can readily deploy and therefore it could be a tool to be added to the art therapist's

preferred applications.

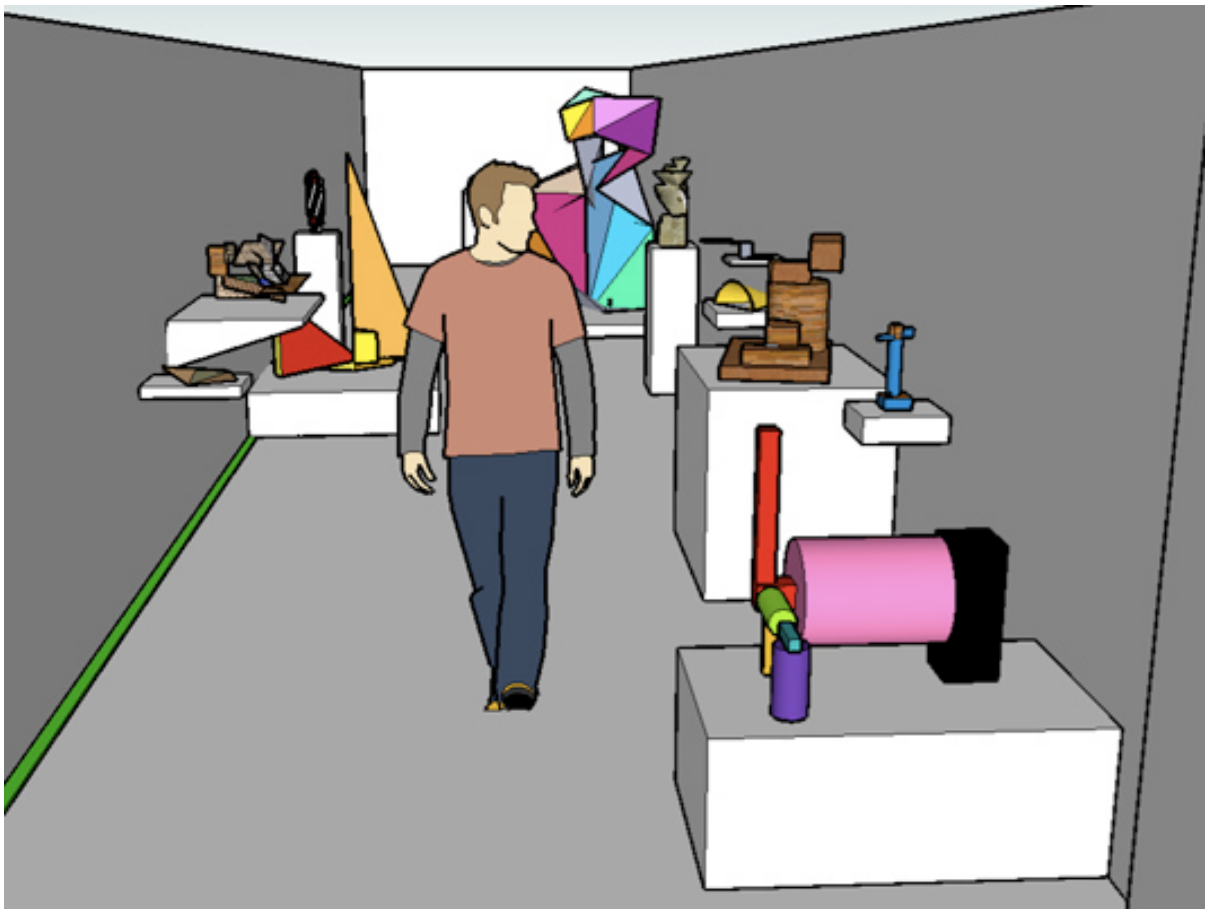


Fig. 1 Stephanie Syjuco Shareware Sculptures Google SketchUp (2009).

Cosmic Blobs

Created by Dassault Systemes, developers of 3D design software, Cosmic Blobs is a powerful 3D graphics software programme invented for children. Recommended for ages 7-14, it allows the user to quickly design and build high-quality 3D creations. Although the interface is childlike, resembling a colourful chemistry lab, the 3D modelling techniques would engage older adolescents and adults as well. In the lab, users intuitively apply 3D sculpting processes like stretching, squeezing and rotating. The completed blob can have elegant lines and there are hundreds of possible colours and textures. Later, the blobs can be animated, e-mailed to friends, printed, or imported into other applications (Dassault Systems, 2013).

Kid Pix

A child-oriented painting program, Kid Pix has several applications including drawing, painting, stamp art, slideshow production and animation. There are various versions: Kid Pix studio deluxe, Kid Pix Studio 3, and Kid Pix Studio 4. This programme seems to be popular

with elementary school-age children and is mainly suited to that age group or developmental level. Children who have access to a computer at home or at school are often familiar with the programme. This is an added benefit to the artist or art therapist when time is of the essence in settings such as hospital bedside where there can be interruptions for vital signs, family visits or doctor's rounds (Malchiodi, 2000, p. 40).

People Putty

People Putty is a tool that allows you to make your very own interactive 3D talking head by altering the pre-made faces and shapes available in the program, or by loading an image from your digital camera, scanner or hard drive. In the texture palette, you can add wrinkles, make-up, hair, alter teeth, eyes, as well as add tattoos or wounds. In the shapes palette, you can mould your character like putty or choose from many shapes that resemble animals and objects. In the personality palette, you can give your character a range of emotions, from broken-hearted to raging mad. The accessories palette includes items such as earrings, glasses, wigs, hairstyles and neckwear. Finally, the theatre palette is where everything comes together. When you record your own voice (or use the available sound clips), your character instantly lip syncs to your words. Additional animation features allow you to send your character moving across the screen, changing shape and expression over time (Haptek, 2013).

Flying Colours

Primarily a stamp and draw application, Flying Colours is advertised to be appropriate from age eight upwards. While the savvy computer artist might find this programme too childlike, the available stamps, backgrounds and vivid moving colours will engage most users. Some of the palettes encompassed within the application are colours, patterns, gradients, a stamp tool and browser, eraser, mover, zoom, eyedropper, polygon tool, oval tool, rectangle tool, bucket fill, line tool, spray can, brush, text, symmetry and stencil. Parker-Bell took note that 'there is no racial or age variety in available figures. Human figure stamps are limited to blond and blue-eyed Caucasians in one adult range and few poses' (1999, p. 182). Although Flying Colours 2 has made an effort to expand the variety of their human stamps, they are still fairly stereotyped. Personal customisation is possible by cutting and pasting desirable photographs into the stamp browser (Flying Colours, 2013).

Photoshop Elements

Now easier to use, this all-in-one home photo solution provides photo editing functionality, plus intuitive organising and sharing capabilities. Photos can be organised using tagging, searching and viewing options. They can be edited by brushing away flaws, clicking away red eye, and cropping and rotating the image in creative and inventive ways. Photos can be converted to sepia or black and white, various effects can be applied and you can simulate painting for artistic enhancement (Adobe Photoshop Elements, 2013).

Photoshop CS (Creative Suite)

Used by graphic and web designers, photographers and video professionals alike, Photoshop's key features include: a full assortment of painting, drawing, and retouching tools; professional colour-correction tools; enhanced layer control and layer compositions; improved file browser; advanced web capabilities; the healing brush; special effects filters; advanced type control; a customisable workspace; and automated production tasks.

Photoshop can seem daunting the first time it is used. It can appear too technical and not the immediate art medium that an art therapist or artist needs in a situation where time is limited. Regardless, Photoshop can be a powerful tool to make art with. If the surrealists and Fluxus movement had had this programme they would have taken full advantage of it. Any art form with a collage lineage would find that this program has something to offer. Young people love this programme for the ability that it has to combine and edit realities to communicate the abstract. Collage and painting in Photoshop lend themselves well to the therapeutic process, being especially useful for expressing emotion (Adobe Photoshop Creative Suite, 2013).

Effusio

This application encourages you to express your feelings visually. It was developed by Shannon Widmer with consultation from Sairalyn Ansano, LCAT. This is the one example that I could find of an application where an art therapist was consulted about its design and which was created with the creative arts therapy community in mind. Effusio allows you to describe your overall mood by choosing an appropriate word and then making it more expressive though choice of colour, type styles and warping. There is a main mood board where, in addition to the words, you can also draw, paint, design and listen to therapeutic music in order to explore complex emotions. I downloaded this software onto the

computers at 'The Hub' UCLH MacMillan Cancer Centre to try it out with TYA cancer patients. I found that the skeumorphics drew attention to the fact that you were not actually using traditional art materials and that you were not really at a desk pinning up little pieces of paper with random emotions written on them to a corkboard. Overall, I found it a disappointment and it served to illustrate that it could be better to use traditional art material to effectively achieve the same end (Widmer, 2013).

Adobe Flash

Flash is popular with web designers, allowing them to create animated websites containing graphics, games, cartoons or movies. It is favoured for its interactive capabilities. Thanks to very small file sizes, it has the added advantage of being quick to load and it also has the ability to stream media. Streaming means that the animation will start to play before the whole file is loaded, thus saving time. Macromedia created Flash and sold it to Adobe in 2005; it is now referred to as Adobe Flash. It is now standard that many computers already have Flash players installed.

Adobe Flash is my favourite programme. I deployed Flash in my animation classes at the Community School of Music and Arts in Mountain View California for three years, as well as in animation workshops while in residence with Citizens of Europe Artists Interventions in Serbia, funded by the Swiss artist fund. I have employed Flash in my own art practice, exhibiting my animated films in galleries and museums. I used Adobe Flash Professional as a research evaluation tool at 'The Hub' UCLH MacMillan Cancer Centre while teaching animation workshops (Adobe Flash Professional, 2013).

Therapeutic benefits of animation

The organisation Animation Therapy received a NESTA grant in 2008 to research the occupational therapy benefits of analogue stop-motion animation recorded using digital cameras and computers to play back the client's creations. Beyond any doubt, animation as a process has many therapeutic qualities such as aiding in exploring emotions, developing social skills, skills-based training (for example, anxiety and anger control programmes) and can be taught on an individual basis or with groups exploring alternative endings and potential consequences.

An example of this approach in education is where personally constructed animated vignettes are used to explore personal choices and consequences, exploring emotional

literacy in schools drawing on interactive technology (Baily, Tettegah and Bradley's 2005 computer programme Clover) and character education. Animation crosses generation gaps and is also accessible to people of all ages (Tettegah et al., 2007). There does not yet exist a flexible digital art programme designed with the art therapist and arts in health worker specifically in mind. There is a need for a programme that could be used in an improvisational way, to suit a variety of therapeutic activities and arts interventions. Until then I appropriate Flash. Flash is a mature program that is sophisticated while still remaining accessible. This is why it is a suitable programme to work with teenagers and young adults. It is quite intuitive and has the capability to save a library of images and psychological artefacts drawn and curated by the user to work within a motion graphic narrative.

Flash is an appropriate program to model aspects for a digital therapeutic prototype. A computer-based tool can enable better expressions of personal experiences than paper can for people who are accustomed to digital culture. The current state of user experience feels like it is too subjective to the designer's experience. It can be beneficial to create a stage where the graphics can be experienced objectively, and then the user can apply their own subjectivity to what they are working on rather that it being branded by the software company's aesthetics and vision.

Mindful technologies

For an art programme to be user-friendly and more familiar, a design process that reduces unnecessary noise and visual elements is vital. This process leaves to remain the most effective tools for the chosen art therapeutic activity. This being said, I have come to find relevance to my research in the work of a team at Stanford University in California pioneering 'mindful technologies'. These technologies have the potential to change attitudes and behaviours through persuasion and social influence. Persuasive techniques change behaviour by framing the perception and shaping the interaction with technologies in ways we often do not recognise.

Mindful technologies focus on engagement with one's mental and emotional state as a medium for behaviour change and well-being. An inspiration for this area comes from the concept of mindfulness. Mindfulness as a developing scientific process has dramatic effects on an individual's mental, physical and emotional well-being (Grossman, 2004). In fact, researchers experimentally compared mindfulness-based therapy against morphine injection and found patients perceived 40% less pain with the mindfulness-based approach.

With its roots in Buddhist mindfulness meditation, mindfulness practices can take any number of forms, for example breathing, yoga and walking.

Different schools of mindfulness have different definitions, but a common definition is the development of awareness and paying attention to intention with an open, non-judgmental attitude (Shapiro et al., 2006). The ways that you use computer graphics programmes for art therapy and art education can be potentially mindful. The art therapeutic programmes I am researching could fall under the category of *mindful technologies*. There is a movement of people in the world, mostly in Northern California, who have been gathering at a conference called Wisdom 1.0 and 2.0 to discuss the potential of an enlightened approach to technology and the potential of *mindful technologies* in the world of computers, technology and social media.

What exactly is *mindful technology?* For the purposes of this thesis, I define it as technology that helps people reflect on their behaviour, whether or not they have goals and whether or not the system is aware of those goals. I would put apps like Last.fm and Dopplr in this category, as well as a lot of tools that might be more commonly classified as persuasive technology, such as UbiFit, LoseIt, and other trackers. While designers of persuasive technology are steering users towards a goal that the designers have in mind, the designers of mindful technology give users the ability to know their own behaviour better in order to support reflection and/or self-regulation in pursuit of goals that the users have chosen for themselves, for example, emotional well-being, spiritual development and self-knowledge.

The computational tool Clover, created by the computer science department at University of Illinois, USA, in 2006, could be considered to be in the sector of mindful technologies in the way that the tool merges technology and 'Character Ed' in grades K-12. Character education refers to teaching ethical values such as caring, honesty, respect, fairness and tolerance from a secular perspective (Bohlin et al., 2001).

Mindfulness and character education share many of the same ideals. Art therapy as a field has much in common with mindfulness, or more precisely, it promotes similar outcomes through guided art-making with an experienced therapist. In a quantitative trial of mindfulness art therapy targeted towards women with cancer, Monti et al. (2006) found that those who engaged in art making demonstrated statistically significant decreases in symptoms of physical and emotional distress during treatment. In addition to the guided imagery, the art-making therapy involved the women drawing complete pictures of

themselves and engaging in yoga and meditation. Relaxation and symptom reduction were produced by creative expression successfully opening pathways to emotional healing.

Out of the projects aforementioned my research has the most in common with the Clover software used by teachers in America. My research works at the intersections of art therapy, arts in health, animation, digital arts and computational technology. What is shared is the intent to integrate qualities of mindfulness into a computational tool with the end result being that the user can experience digital media in a mindful way.

Digital art in hospitals

An example of an artist employing mindful technology is Brian Eno in his installation at Montefiore Hospital in Brighton and Hove, UK. In April 2013, the hospital collaborated with the ambient music artist to create a 'quiet room' where patients can find relaxation and calm. Eno designed a light and sound installation for the room and for the reception area, including an original soundtrack of soothing instrumental tunes. Once the room has had a few inhabitants, there are plans to examine whether the patients who have sought solace there exhibit any beneficial physiological changes. This is one of only two projects of this kind in the world housed within a hospital environment.

The second example is Eno's famous *77 Million Paintings for Montefiore*, an installation of light and generative music in the reception area of Montefiore Hospital. I attended a screening of the original *77 Million Paintings* about 15 years ago in San Francisco. I recall it as an important moment for me, to know that digital art can be accepted institutionally on such a grand scale. Architects IBI Nightingale, propose that, 'Creating a healing environment isn't only about correct surgical procedures and the right technology but also about making an atmosphere where the patients feel able to relax enough to clearly think through their options, and to properly take part in the healing process themselves' (Nightingale cited in Sherwin, 2013).

Eno says that he was directly inspired by the words of Nightingale: 'Variety of form and brilliancy of colour in the objects presented to patients have a powerful effect and are actual means of recovery' (Sherwin, 2013). Eno hopes to create more installations and is working from existing research but has yet to generate any research based on his own experience with patients (Sherwin, 2013).

This project raises some issues concerning aesthetics. Not everyone is automatically an Eno fan. Planting an immersive art installation in a hospital where people may not have

any choice but to situate themselves nearby can be problematic if the installation does not meet every individual's code of aesthetics. According to the hospital, data will be collected post-installation of the piece *in situ* to evaluate if the artwork has promoted any well-being benefits for visitors. Brian Eno's status as a renowned and established artist could be problematic. His work installed in the hospital is executed with no previous quantitative or qualitative research concerning computational technology, health and well-being. His work could be called into question with regard to ethics and the needs of patients and medical staff.

Distraction versus analysis

I have experienced a distrust of art therapy in the sense of fear of analysis, by the staff in the hospital environment, while volunteering at UCLH. The nurses observe that patients do not want to explore their discomfort, although they benefit from activities that take their mind off what is happening to them in the clinical environment. The nurses have accepted and are promoting the digital art activities that I offer to the patients and view the activities that I offer as a distraction method. The nurses and play specialists are currently using other methods of distraction, like the portable 3D V-pod distraction system that has been developed by Middlesbrough-based company Amazing Interactives (Amazing Interactives, 2013).

I have, however, found that through speaking with the play specialists at UCLH MacMillan Cancer Centre that it is underutilised for pain reduction and more often used for amusement by younger children. The system was originally designed to provide a visual distraction for children undergoing surgery in hospital and having received positive feedback from children and medics, is now in regular use at more than 20 of the UK's leading children's hospitals. The portable 3D technology features rollercoaster rides and cartoons to capture the attention of children as well as relaxing underwater scenes and woodland views to soothe nervous patients. There are also programmes that address the areas of adult/child post-traumatic stress, Alzheimer's, dementia and childbirth. In areas of mental trauma, the interactive 3D system will soon be linked to the pulse rate of the patient via an oximeter. This will allow the patient and the specialist to actually see what causes anxiety levels to increase in real-time 3D. Amazing Interactives make the claim that specialists can then teach the patient how to control anxiety using the 3D system.

I had the opportunity to test this instrument while volunteering at UCLH. There was a

device that controlled the graphics on the screen by blowing into it. When I tested it there was a control system that was activated which scattered the 3D visuals on the screen according to how lightly or strongly you blew. I can say that it was novel, but I think that gesture control may be a simpler way to manipulate the graphics. There was a variety of graphics to choose from, such as tropical fish, roller coasters and bubbles. I chose the tropical fish. When I blew softly the fish swam slowly and when I blew harder the fish became more active. The screen was quite large and slightly curved to give the illusion of total immersion. The fish protruded slightly into the room because of the 3D glasses that are provided to wear. The visuals were quite generic. I could see the appeal for very small children and that it could serve to distract them, though overall, I think that the system has room for improvement.

Another example of the healing potential of digital media is an avatar system that enables people with schizophrenia to control the voice of their hallucinations. Researchers at UCL are developing it now, with support from the Wellcome Trust. The computer-based system could provide quick and effective therapy that is far more successful than current pharmaceutical treatments, helping to reduce the frequency and severity of episodes of schizophrenia. The team has now received a £1.3 million translation award from the Wellcome Trust to refine the system and conduct a larger, randomised study to evaluate this novel approach to schizophrenia therapy. The study will be conducted at King's College London Institute of Psychiatry.

My art practice research is firmly grounded in theories of 'arts in health' and computational technology. I adopt research that supports the presence of art on display as well as an activity that promotes healing and well-being. The healing power of art and practising art as a community ritual is fundamental to this research.

Shaun McNiff, PhD, Professor of Expressive Therapy at Leslie College in Cambridge Massachusetts, is the pioneer in art therapy who is behind the concept of 'art as medicine':

> Whenever illness is associated with loss of soul the arts emerge spontaneously as remedies, soul medicine. The medicine of the artist, like that of the shaman, arises from his or her relationship to "familiars" – the themes, methods, and materials interact with the artist through the creative process. *Art as Medicine* demonstrates how the imagination heals and renews itself through this natural process (McNiff, 1992, p. 2).

Optimists versus pessimists: the future of healing media

Professor Susan Greenfield, the well-known neuroscientist, cites that she is so familiar with the malleability of the human brain she predicts that spending too much time in cyber-space will inevitably lead to minds being very different from any others in history (Greenfield, 2008, p. 160). Her prediction seems to be a reality already. She believes the new unprecedented environment brought about by current technologies might enhance a tendency for recklessness; if so, in the future we will need to manage that environment to encourage just the appropriate degree of risk taking. As a neuroscientist she wonders what the brain will physically look like in future generations. Her central anxieties are that galloping technological advances and the social changes that they bring will not only transform our sense of who and what we are, but might alter our identity to the point where we may no longer have the capacity to be fully developed individuals (Greenfield, 2008).

Her prediction is that interaction with technology, from mobile phones to video games, might produce a brain as a first-person perspective of identity that is stuck in what she terms 'infancy immediacy'. Twenty-first-century technologies may bend our brains, and hence erode our identities, she argues, in ways that previous generations could not have envisaged. However, none of the interesting questions about subjective identity and objective identification is explored by Greenfield in *ID: The Quest for Meaning in the 21st Century* (2008).

On the other hand, literary and media theorist Katherine Hayles cites that the brain is mutating to work with numeric media as a positive evolution that is happening and needs to be recognised and adjusted accordingly.

'Through a process known as synaptogenesis, a new-born infant undergoes a pruning process whereby the neural connections in the brain that are used strengthen and grow, while those that are not decay and disappear' (Bear et al., 2007, cited in Hayles, 2008). The evolutionary advantage of this pruning process is clear, for it bestows remarkable flexibility, giving humans the power to adapt to widely differing environments. 'Although synaptogenesis is greatest in infancy, plasticity continues throughout childhood and adolescence, and to some degree continues even into adulthood. In contemporary developed societies, this plasticity implies that the brain's synaptic connections are co-evolving with environments in which media consumption is a dominant factor. Children growing up in media-rich environments literally have brains wired differently from humans who did not come to maturity in such condition' (Hayles, 2008).

Hayles analysed this mutation and has described it as a generational mutation in the form of a cognitive change in attention levels. This mutation occurs through what Hayles calls *hyperattention,* which she opposes to *deep attention.* She characterises deep attention as the capturing of attention by a single object, sustained over a long period of time, for example reading a novel by Charles Dickens. Hyper attention, in contrast, is characterised by a rapid oscillation among different tasks, in the flux of multiple sources of information, in search of a heightened level of stimulation, and having a weak tolerance for boredom. Developed societies have for a long time been capable of creating the kind of environment in which deep attention is possible. A generational mutation has taken place, transforming deep attention into hyperattention (Hayles, 2008).

From Hayles' perspective, she observes that this mutation has happened and is not new, so what is going to be done about it? She contends that there should be no doubt that hyperattention came before the mode of deep attention as a mode of basic survival, and that hyperattentive modes are reappearing to establish dialogues with the internet and new media technologies. The answer is not to incite fear and deprogramme this generation, but to work with and for this generation to harvest the advantages this mutation brings with it. Steven Johnson, author of *Everything Bad is Good for You* (2005), optimistically describes how the cognitive abilities of the screen generation are indeed changing, albeit to their advantage.

Their Space, a survey conducted by the thinktank Demos, concluded that new technologies could actually nurture the learning experience, defined in their report as; first, finding information and knowledge; secondly, doing something about it; thirdly, sharing it with an audience; and fourthly, reflecting on it. Wide-ranging skills including risk-taking, social/personal communication, multi-tasking, general knowledge, hand-eye coordination and problem solving were cited among the learning that was acquired by the teachers, parents and children that were polled in the survey. However, the report cautions that there is more involved in this kind of learning than merely providing the appropriate hardware.

Bernard Stiegler and Greenfield share not unrelated concerns about technology. Stiegler has constructed a Star Wars-esque philosophy concerning future generations in his recent book *Taking Care of Youth and the Generations* (2010) in which he narrates with an authoritative yet caring voice of reason. He enters into dialogue with Hayles to issue a warning of the dangers of her theories of hyperattention and deep attention. Stiegler's concern is that the most valuable things that civilization has accumulated are being

systematically destroyed every day with the most brutal *psychotechniques* and weapons of what he calls the *'*programming industry'. This is an umbrella term referring to companies such as Microsoft, Adobe, Apple, social networking sites, video games and the state of California. These companies aim at keeping hold of the public's attention by producing a consciousness directed towards an imaginary object of desire, feeding into and sustaining a system of consumption and marketing.

He blames the evils of this programming industry on the disintegration of family structure and the extreme attenuation of educational institutions. He claims that the unfortunate progress of *psychotechnologies* produces subjects/users that do not identify with parents but with brands. He describes how objects that are engineered and manufactured by the programming industry block the channelling of attention in the brains of our youth to ultimately hijack and take over their consciousness.

He declares that educators must fight against the programming industry's principal motives, which are 'to take control of the process of referential individuation and, in order to do this, to short circuit the education system and all intergenerational relations, be they familial or reconstituted through knowledge as *episteme*, in the Foucauldian[1] sense, and reason – particularly as the reason required to live together' (Stiegler, 2010, p. 77) *Taking Care* could easily be read as a pessimistic account of the triumph of hyperattention over deep attention by way of a supposed linear shift.

Echoing Stiegler and Greenfield, the American technology writer Nicholas Carr calls the internet an interruption system. In his book *The Shallows* (2011), Carr argues that we are experiencing a rewiring of the brain because of our frantic multi-tasking with digital media. He argues, 'The web encourages us to click and flick. Soon all our brains want to do is click and flick. We stop reading novels and before you know it, 'the linear, literary mind' becomes 'yesterday's mind'' (Carr, 2011). Carr puts together an informative history of brain science to back up his argument. The latest neuroscience says that our grey matter is malleable and plastic. As the internet remoulds and rewires the brain in its image, the old book-reading circuits fall out of use and wither.

[1] Michel Foucault used the term episteme in a highly specialised sense in his work *The Order of Things* (1970) to mean the historical *a priori* that grounds knowledge and its discourses and thus represents the condition within a particular epoch. In subsequent writings, he made it clear that several epistemes may co-exist and interact at the same time being parts of various power-knowledge systems. But he did not discard the concept.

Steven Johnson (2005) argues from a different perspective. He has a concept called the 'sleeper curve' which he thinks reveals the increasing sophistication of modern popular culture especially amongst the Millennials and Post-Millenials, which is anyone born post-1981. Johnson finds 'a cocktail of reward and exploration' born of a desire to play some kinds of video games. That is active, highly personal, sociable and creative. The complexity of some video games, for Johnson, offers satisfaction via the complexity of the worlds we are asked to inhabit, a social gaming within a social networking of hanging out to create new forms of social interaction, and the social emotions and that are offered within Playfish. Though for some critics, such as UK Guardian newspaper's Steven Poole, Johnson's work is 'most interesting as an example of a particular philistine current in computer-age thinking' (Poole, 2005).

The perspectives of the preceding authors are particularly relevant for my study group, which is made up of Millennials and Post-Millennials. They may all be faced with theories that their brains are different from those of other generations before them. They may also be the direct targets of what Stiegler calls *psychotechnologies*. By researching directly with teenagers and young adults, the narratives of technology through the perspective of Millennials and Post-Millennials are captured through digital ethnography to be analyzed.

What now? Seeing the light: a healthy direction for technology

While my research is distinctive is in its methods, and in its contribution to the dialogue around arts in health, it encourages the emergence of the therapeutic and positive aspects of these technologies, without becoming vulnerable to the unhealthy marketing circuit that captivates our attention and desires in order to service negative commercial agendas.

Sherry Turkle, in *Alone Together: Why We Expect More from Technology and Less from Each Other* (2011), considers how technology affects the younger generation's definition of life, death and authenticity. She suggests that the mid-1990s saw a turning point for her research. She describes two key developments, the first being the 'fully networked life' in which we are infinitely connected to anyone from anywhere, and the second being the robotics movement. Turkle argues that what connects these two seemingly disparate topics is our reduced need for authenticity, especially within the younger generation. Turkle even documents cases where some children begin to preference their

robotic pet over their current organic ones.

Turkle's anxieties about teenagers constantly performing on the digital stage, to incipient roboticism, the 'robotic moment' is not a cultural phenomenon in history but a threshold in ethics. Ethical questions start to surface when we see robots as having subjectivity. Turkle is concerned about the way we set up such important social, ethical questions, 'quandaries' she calls them, such as: 'Do you want seniors lonely and bored, or do you want them engaged with a robotic companion?' She wants to make sure we consider moral issues not only when setting up a quandary, but also when responding to it. Turkle takes on this task by questioning how we think about our relationship with technology; therein lies the challenge posed by *Alone Together*.

Finally, Turkle suggests through what she calls 'realtechnik' that we step back and reassess when we hear triumphalist or apocalyptic narratives about how to live with technology. Realtechnik is a form of scepticism about linear progress. It encourages humility, a state of mind in which we are most open to facing problems and reconsidering decisions. It helps us acknowledge costs and recognise the things we hold inviolate. 'I have said that this way of envisaging our lives with technology is close to the ethic of psychoanalysis. Old fashioned perhaps, but our times have brought us back to such homilies' (Turkle, 2011 p. 294).

Turkle advises that we need not reject or disparage technology. On the contrary, we need to put it in its place. In order for the generations to move forward together we are called upon to embrace the complexity of our situation. Even though we have invented inspiring and enhancing technologies we still feel that somehow, we allow them to diminish us. This relationship with technology is poised to change. It is time to address the vulnerabilities of this new generation. They feel that they are deprived of attention even though they are constantly connected via digital devices. These are the children who were pushed on swings while their parents spoke on cell phones. These same parents now do their e-mail at the dinner table (Turkle, 2007, p. 294). The familiarity and constant presence of technology in the lives of Millennials have made Millennials and technology inseparable.

This constant connectivity and its particular issues call for new and innovative solutions. I will now call upon what Stiegler refers to as the *pharmakon* (something that is both poisonous and therapeutic at the same time) as a possible creative solution, for example, my deployment of Adobe Flash, a *psychotechnology*, as an instrument to make art and as an assessment tool to measure outcomes of health and well-being benefits in the

hospital setting. This is made possible by entering a space where these young people exist and by making contact through a transitional digital object. Turkle contends that 'life on the screen can be working material for psychotherapy, not something that therapists should discourage as a waste of time' (Turkle, 2008, p. 23).

Turkle published *The Second Self: Computers and the Human Spirit* in 1984, where she described the changing relationship between people and technology, particularly computers. At the time she questioned the effect these new technologies were having on our lives, relationships and cognition. This is a theme that still runs through all of Turkle's work as she analyses the changing role and social positioning of technology and human beings over time. In 1984, Turkle was already questioning whether 'machines' were truly an extension of their users or whether they were something 'other'. She defined machines as something 'other' if they imposed their own rhythm, pace and rules onto the person using them.

In this case, Turkle observed, rather than humans simply using computers to extend their physical capabilities, as was previously the case with tools, the computer actually affected human cognition. Through sustained interaction computers have successfully altered our pace, rhythm and sense of self. As society becomes more complex, we develop new technologies to cope with our current situation, assuming that this will make things easier. How we think about our relationship with technology is what underpins my research and fuels my inquiry into healthy relationships with technology through researching and developing digital art-based research methods.

Translating traditional art media into digital art media for healthcare

Research from Staricoff's review (2004) shows evidence that there are health and well-being benefits through participation in art interventions that employ traditional art mediums with patients. For example, the key findings in the review of the effect of the arts on clinical outcomes reveal that visual art and live and taped music have been used in a number of studies addressing high anxiety and depression during chemotherapy. The arts were effective in reducing both anxiety and depression and acted as a potent adjuvant to avert side effects of the treatment (Staricoff, 2004, p. 6). What my research proposes is that, with considered research and development, the beneficial aspects extracted from existing evidence can inform the production of an innovative digital art therapeutic prototype. This underlies the formulation of my research questions.

The emotional reaction to viewing pictures has also been explored. Researchers at the Department of Clinical and Health Psychology, University of Florida, Gainesville have measured facial reactivity of subjects involved in an experiment evaluating their affective judgment and interest, and their behaviour in voluntarily terminating the exposure to the visual stimuli. The experiment used coloured photographs of domestic and wild animals, human faces and pictures of social interactions. The results showed that facial expressiveness induces specific emotional responses and that intensity of interest and length of viewing times are associated with the degree of pleasure and arousal elicited by photographs. Although some differences were found between males and females, the affective responses were largely independent of personality factors (Lang et al., 1993).

This evidence supports the work of Dennis Roche in his project 'Open Windows' where he projects a stream of images in the room of a person in recovery. Family and friends have permission to remotely upload images that are projected. People who know the patient intimately can determine or prescribe what images could have a positive effect on them and make them happy.

An intriguing question is how the brain is able to connect piano keys, piano sounds and the actual skill of piano playing. The responses of how groups of people, one with no musical experience and the other consisting of professional pianists, were tested listening to a melody, adapting to a practising procedure or pressing the keys on a silent piano. The results showed a similar distribution of the activated areas of the brain in both groups. Practising develops the capacity of co-representing sound and movement like a map in the brain. This is one of the models used for understanding the mechanism by which the motor system (movement of fingers) under auditory control responds to the high demands of the quick and precise coordination required for playing the piano (Bangert et al., 2001; Andrade et al., 2003).

The relationship between colour and emotions has been studied from a psychological point of view (Barber, 1999). Although further research is needed to establish the biological mechanisms underlying this process, the implications of this study is of great significance. Understanding how and which emotional response is triggered by colour and sound enables its rational use in creating a powerful therapeutic environment. The most obvious surrogate for an actual piano would be a keyboard, which could be synchronous with a specialised colour and form software. Digital media would appear to be the most portable way to experience this kind of therapy in the hospital setting, including at the bedside. This

experience can be created by experimenting with existing user-friendly file-sharing networks like Tumblr or Flickr with music of your choice. An external keyboard can be plugged in and practised on to exercise motor co-ordination.

The conceptualisation and construction of an assemblage of existing digital media platforms to promote health and wellbeing is an example of how 'inventive methods' (Lury and Wakeford, 2012) can lead to prototypes for healing media. The notion of assemblage is taken from the work of Deleuze and Guattari in *A Thousand Plateaus: Capitalism and Schizophrenia* (1988). Andrii Glushko explains:

> Hospitals and private practices are adapting electronic systems to run portions of their business, requiring features and tools to be combined in order to satisfy the needs of the patient. This is where different domain specialists can help design complex services while not making them too complicated (Glushko, 2013).

This is where my observations at UCLH and working closely with patients in the digital art workshops inform and assure optimal design for the digital art therapeutic prototype and potentially through the testing of the final prototype. From what I have observed while working with the teenagers and young adults at UCLH, I am in agreement with Glushko that design and services are in need of less complicated devices as well as environments to fully experience new pathways to healing.

Conclusion

While researching for this literature review it became evident that there is an opportunity for design input from artists and particularly women artists when developing and conceptualising art-making software. If the software is going to be adopted with enthusiasm and regularity by art therapists and arts in health workers, it is necessary for it to embody the qualities that they value and find effective in traditional art mediums. It is also apparent that the large body of extant research related to the positive effects of the arts and humanities in health care has much to explore by way of the digital art medium.

It is from this information that I draw the conclusion that there is a unique contribution to be made by me as an artist-researcher and arts in health worker, through performing digital art-based research with the teenagers and young adults at UCLH MacMillan Cancer Centre. This can be done through probing the effects on health and well-being via the facilitation of creative digital art activities. The literature that I have reviewed

has led me to believe that data collected by arts-based researchers practising inventive methods in the healthcare setting have valuable insights that could help inform further development of novel digital arts-based research methods.

Speculative conclusions

Drawing from extant research concerning the health and well-being benefits of participation in traditional art mediums and viewing performance and music I deduce that digital arts and animation have the ability to produce similar benefits as well as their own unique contributions. That being said, the concerns raised by the literature review about lack of artists' and women's input into digital arts programmes lead me to speculate that if there were more women and women artists involved in the design and engineering of digital arts applications, the final product may be more readily adopted in the art therapeutic professions and into the arts in health activities in the hospital setting.

In summary this chapter charted existing literature that documents health and wellbeing effects of art interventions that make use of digital art media from as early as 1985 until the present. What is revealed is that there is a paucity of research that uses digital art-based research methods in art therapy and the medical environment. The challenging relationship between art therapists and digital art media is also uncovered. Additionally, the roles of Arts in Health workers and Art Therapists are distinguished between in healthcare settings. A software review of off the shelf digital art programs that are used by artists and art therapists is included, alongside the therapeutic benefits of animation. Mindful technologies, Digital art in hospitals, distraction versus analysis and the optimist versus pessimistic views of the future of technology within healthcare is taken into critical account.

This chapter ends with an optimistic direction for technology within the healthcare setting concluding that digital art programs could be more effective and adopted by art therapists if the research and development process involved more stakeholders such as women programmers, artists and art therapists. The following chapter addresses the methodology and study design for this research.

Chapter 3: Methodology and Study Design

In this study I use a mixed methods approach that draws on co-design, narrative analysis, digital visual ethnography (DVA) and experimental ethnography (EE), body mapping and constructivist grounded theory (CGT) (Charmaz, 2000). My methods and methodology blend and reflect existing practice-based and interdisciplinary frameworks such as inventiveness and collaborative methods in 'the happening of the social' as suggested by Lury and Wakeford (2014, pp. 2-7), practice as research (Nelson, 2013), and relating theory, practice and evaluation in practitioner research (Edmonds & Candy, 2010). I visualise the entirety of this work metaphorically as individual interwoven layers. There is the layer on top that is visible and there are the layers beneath that affect and permeate the whole while remaining unseen.

The base layer furthest from the top is CGT, acting as the foundation and framework of my research. The next layer is co-design (CD), then narrative analysis, then digital visual ethnography, with the final top layer being body mapping. The decision to use body mapping is the result of experimentation with different methods and finding that it functions to collect data successfully in multiple ways. It became the main method that I used to capture visual ethnographic data that remained prominent once the layers merged. Below I define CGT and each method and their interdependence and interrelatedness to each other.

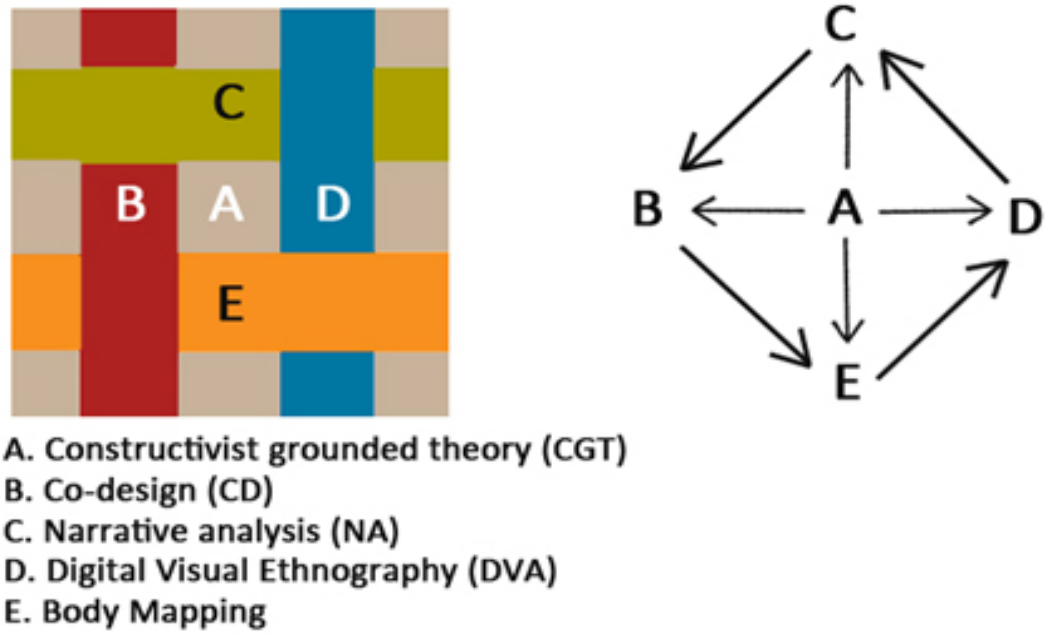


Fig. 2 Visualization

Co-design

Co-design (CD) is a method that is being used to a greater degree within the business, health and social sectors (Bradwell & Marr, 2008). The main features are participation and collaboration while designing with, and not only for, participants. With the TYAs in the hospital setting I created a living digital arts lab as described by Telier et al. (2011). This lab and others aim for co-creation with real users on a long-term basis and show how the discipline of design is grappling with questions of ethics and pragmatism (Telier, 2011, p. 179). The participation and voice of the TYAs and other stakeholders in the living digital art lab has become a significant portion of the research data. Scrivener (2005) stresses in his writing for the editorial of the first edition of *CoDesign* magazine that the term CD seeks to create a framework for debate, while at the same time being able to encourage a freer kind of thinking that does not constrain ideas into a narrow mould. He describes it as an umbrella term inclusive of participatory design and community design. Albinsson, Lind and Forsgren (2007) propose that CD is the answer to the need for 'constructive meetings between several stakeholders' (Albinsson, Lind and Forsgren, 2007, cited in Bradwell & Marr, 2008, p. 17).

The international survey of public service CD (2008) articulates a four-part working definition for practitioners, beginning with participation and the idea that CD is a collaboration. This process is extended by several features, such as transparency through making all participants aware of the design methodology, the goals of the study and who and what it is for. Interaction with participants on a regular basis ensures the creation of close working relationships. CD aims to collect input from all stakeholders, reflecting the multiple viewpoints affecting the community of the research involved. The second part is development, proposing that CD is a developmental process and explaining that the subject of the design process exchanges knowledge and skills with the researcher/designer as well as the reverse; 'In this sense co-design teaches co-design' (Bradwell & Marr, 2008, p. 17).

The third part, referring to ownership and power, describes how CD creates a sense of collective ownership with those involved in the study by maintaining a balance of freedoms and rights among the participants. Through placing value and legitimacy on the participants' voices, an equal platform is established. This is recognised for large and small enquiries, resulting in a more even distribution of power. The fourth assertion, outcomes and intent, concludes that CD activities are outcome purposed, having a direction that is clear and pragmatic. The methodology and application aim to foster mutual constructive

motivations amongst all participants (Bradwell & Marr, 2008). An important characteristic of the CD best practice environment is that the communication and context build a safe space for the participants to express themselves. In the case of my study they create digital and traditional art forms. In this space they are free to put forth unfavourable or controversial suggestions or images without any possibility of negative consequences (Bradwell & Marr, 2008).

Narrative analysis

Narrative analysis (NA), or journaling, as the name implies, focuses on the study of stories or accounts, usually of individuals, but also of groups, societies and cultures. NA or narrative methods are a product of what was termed the 'narrative turn' in social science research, which has been described and analysed as a response to the lack of human stories in traditional social science in the 1960s. The narrative turn was ushered in during the early 1980s with the publication of *On Narrative*, edited by W.J.T. Mitchell in 1981. For the first time, narratives were understood as data and theory for research purposes. More currently, Mark Freeman, cited in Ruppel, Dege and Squire (2008) argues that 'narrative inquiry, insofar as it aspires to be faithful to the phenomena, can open the way toward a more expansive, and adequate, conception of science itself than is often found in the social sciences' (p. 33). The method of site writing enacts a novel kind of art criticism that Jane Rendell professor of architecture and art at the Bartlett School of Architecture UCL, proposes 'draws out its spatial qualities, aiming to put the sites of the critic's engagement with art first'. Site writing 'investigates the psychic qualities and architectural dimensions of a particular spatial condition' (Rendell, 2011).

Site writing as a form of NA relates to my journaling and is included in this thesis because I prioritise the architecture of the UCLH MacMillan Cancer Centre and the situatedness of my study within the TYA cancer ward. It is here that I did my observations and journaling of the participants and the art activities that took place in the living digital lab as well as the site where the participants' digital art and the process can be viewed in real time. It is not the art criticism itself that is relevant to my study but the emotional, political and conceptual engagement process that the art writer goes through while evaluating all the different aspects of the site of the artworks. The hospital is the architecture and the stage for my journal entries. Below is a sample from my journal entries:

October 6, 2014

I am going to take the opportunity to write about the fragile and sensitive environment that I conduct my observational studies in. The relationship that I have with the physical space that I occupy as simultaneously a guest, host, support service provider, artist and volunteer. All of these roles functioning at once require delicate and engineered decision-making at all times. Making observations while I am doing digital art projects with the teenage and young adult cancer patients requires me to have a good memory.

There is a very particular and careful etiquette that is necessary while interacting with workshop participants. It was quite easy to engage with this particular patient (he will be referred to as E. E.; he is around 19 and male). He was open to trying either the Adobe Photoshop or the Adobe Flash animation. We decided we would try the Photoshop abstract auto-portrait collage first. He chose three images: an image from the movie *Rush* that is about two famous race-car drivers; an image of a deceased 1970s famous race-car driver; and an image of a racetrack at Monte Carlo. E. E. was different from any of the other patients that I had worked with before because he took the time to explain what the images were and why he chose them to represent himself in an abstract way.

He explained to me how the racetracks were set up and broken down to be set up in different cities. He explained that the picture of the race-car driver looked like his father, whom he does not see very often because his parents are divorced. The interaction that I was experiencing with E. E. was fragile and intimate. It felt as though the computer was facilitating the dialogue between E. E. and me. I gave him a tour of Photoshop, and he placed one image right in the middle of the page arranged as landscape. He placed the two other images symmetrically on the page.

Normally I show the patients how the tools work and the different effects that you can achieve with minimal effort. Usually the patients get very involved in the tools. E. E. was different in the way that he wanted to talk more about what he was making and what it meant to him. He shared a part of his personal narrative with me.

Journaling assists me in the collection and analysis of data simultaneously as set out in the actions for CGT. It connects threads of language to images building the participant's story. I act as a witness to the participant's experience. Mark Freeman emphasizes that this mode of writing 'will be less oriented toward arguing, convincing, making a definitive case, than toward appealing, suggesting, opening, pointing toward the possible' (Ruppel et al.

2008, p. 33). I approach journaling with an emphasis on observation and sharing how the participants interact with the digital art media, and the ambience that the clinical environment provides. It is in these archived moments that I can revisit and re-experience the interactions with participants to analyse closely and draw my conclusions.

Digital visual ethnography

hyphy (DVE). To interpret the social organisation, hospital culture and experience of the TYA patients I used digital images and video stills as research data for this study. The computer acted as a communication agent between the participant and myself. Digital media art software is efficient for capturing observations about how participants use the media. To capture and document digital visual data for this thesis I made video stills and jpegs of the digital collages (see Chapter 7). I acquired the stills from animations that the participants made with Adobe Flash animation software and the digital collages that are made in Photoshop.

Rosy Martin, a therapist and photographer, describes working with digital images:

> Digital photography greatly simplifies the creation of alternative diaries. These may then be combined with existing family album photographs, found images and new self-portraits, created in a collaborative manner as in re-enactments, so that the sitter is directing the outcomes. Using image manipulation programmes, such as Photoshop, these can be worked with to create complex layering of images and text, exploring personal 'digital identities', which can become the basis for therapeutic processing, as in traditional art therapy (2012, p. 39).

Martin aptly describes the advantages of using digital media images for collage purposes. It is particularly useful in the case of working with TYAs because of time constraints and the need to adapt projects to suit the available time.

With the Flash animations that are made with similar time constraints, the finished pieces result in autobiographic videos. The videos are moving image narratives that are figurative, abstract or a combination of both.

I classified these videos, jpegs and digital photos as digital visual ethnography because of my relationship to the TYA community as a researcher. The TYA participants experience of receiving cancer treatment at University College Hospital Macmillan Cancer Centre combined with their age range of 14 -24 are important commonalities that create bonding as a group in the hospital culture. That being said, ethnography is 'the art and science of describing a group or culture' (Fetterman, 1998). Ethnographic research with the

use of digital resources has become increasingly significant in terms of understanding our social world (Pink et al., 2015). DVE is particularly effective for research within the subject's environment. Weber (2008) holds the view that 'images can be used to capture the ineffable, the hard-to-put into words … images can make us pay attention to things in new ways … images can be used to communicate more holistically, incorporating multiple layers, and evoking stories or questions' (Weber, 2008, pp. 45-46).

The artworks in the form of videos, jpegs and digital photos represent the digital art cultural artefacts produced by the TYA participants for this study. These artefacts show some of the experience of these young people who were born into the age of digital technology and who are undergoing treatment for cancer.

There is a small number of art artefacts produced by the TYA participants' carers and family members which are included in the analysis. These are considered due to the relationships they have with the TYAs, and with the carers and family members personal wellbeing.

Body mapping

Body mapping (BM) is a story-telling method which I chose to use with the participants. It is an adaptation of a social science research method that was conceived in 2000 at Cape Town University, South Africa, in collaboration with women living with HIV/AIDS (Solomon, 2008). In their manual *Body Map: Storytelling as Research* Gastaldo et al. say:

> Body-map story telling is primarily a data generating research method used to tell a story that visually reflects social, political and economic processes, as well as individuals' embodied experiences and meanings attributed to their life circumstances that shape who they have become. Body-map story telling has the potential to connect times and spaces in people's lives that are otherwise seen as separate and distal in more traditional linear accounts (2012, p. 10).

Solomon asserts in her facilitators' guide that the BM method works well as a participatory qualitative research tool and that the drawings and paintings are in themselves the data and can be supplementary to writing and interviews. As an art-making tool it can be instructional, helping people to learn about art, colour, drawing and composition. As a therapeutic tool it helps to explore identity and social relationships and to develop new directions and fresh insights. As a biographical tool it is able to show and tell about people's lives (Solomon, 2008).

For the adaptation of the BM method I took into consideration the amount of time I would have with the participants. I made the decision to create a brief form of BM, one that reflected the digital experience of 'hyperattention'. With the concept of hyperattention in mind I chose to work with casualty report body diagrams. These are the human outlines that are used to locate and describe injuries for medical documentation. They are also used in autopsies to map out the cause of death.

I photocopied the outlines on A4 paper; one male, one female and one gender-neutral. I also selected outlines of the brain, hands and silhouette outlines of the head (see chapter 2). Inside these outlines the participants were encouraged to abstractly and/or figuratively draw images about what they are thinking and feeling, and to express themselves visually in any way that they felt was safe and comfortable. I made available watercolour-based pens. I brought the project to the bedside while the participants were having chemotherapy. The size of the paper made the task achievable in a short period of time. They could spend as much or as little time on it as they liked (examples in Chapter 2.)

The size of the body map and the usability of the pens is what makes this adaptation a brief and bespoke form of BM for the hospital environment. The patients were made aware that the study was completely anonymous and that they could disclose as little or as much as they wished. Some people wanted to sign their names on their maps and others did not. Some people chose to post their maps on the hospital walls. All of the participants chose to give me their maps for the study, and I observed that they felt a sense of accomplishment upon completion of their body maps.

I went on to develop a group body map at the suggestion of the ward play therapist, Zoe (example in Chapter 2). She had observed that the patients liked to work on projects together and that this was a way to create social interaction. I used a collage method for this suggestion. I drew large life-sized outlines of the body and had the participants cut out images from magazines and place them on the body in creative ways. This version did create a sense of community though it was not as immediate and personal as the brief BM method described above. I included this variation on the method for the purpose of comparative analysis as described by Charmaz (2014, p. 15).

Constructivist grounded theory

Constructivist grounded theory (CGT) emerged from the research methodology grounded theory (GT) as a flexible version that resists the mechanical applications of grounded theory. Ontologically relativist and epistemologically subjectivist CGT reshapes the interaction between researcher and participants in the research process and, in doing so, brings to the fore the notion of the researcher as author (Mills, Bonner & Francis, 2006). CGT appropriates the open-ended, emergent, comparative and inductive GT approach of Glaser and Strauss's (1967) original statement.

GT is a methodology that aims to formulate theory from people's essential concerns in their lives (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998). This is possible through the practice of data collection that is known as 'inductive' (Morse, 2001), denoting that the researcher has no preconceived objectives to prove or disprove. Instead, relevant subject matter from the participants develops from the narratives that they reveal in the field of interest that they occupy with the researcher. The researcher uses comparative methods to analyse the data. Categories are made within the data that are useful for contrasting their interpretations. This consistent juxtaposition of analysis to the field of study makes it achievable for the researcher to ground her final theorising in the participants' experiences.

Constructivism as a research paradigm questions the existence of objective reality 'asserting instead that realities are social constructions of the mind, and that there exist as many such constructions as there are individuals (although clearly many constructions will be shared)' (Guba & Lincoln, 1989, p. 43).

In the 1990s there was a constructivist turn that responded to numerous criticisms of earlier versions of GT. Narrative and postmodern critics undermined GT (see for example Conrad, 1990; Ellis, 1995; Richardson, 1993) on the basis that the methodology adhered to an outmoded modernist epistemology. They thought that the participants' stories were fractured by GT through the researcher's authoritative voices. Charmaz (2000), a student of Glaser and Strauss, is the leading proponent of CGT and the first researcher to describe her work explicitly as CGT. In her work she instructs readers to place the emphasis on keeping the researcher close to the participants throughout the study.

A key technique is creative writing as a form of expression that has the potential to communicate how participants construct their worlds. Charmaz (2000) developed the theme of writing as a strategy in CGT in her later work, when she advocated a writing style that was

more literary than scientific in intent. Charmaz encourages researchers to be authors and include raw data in their theoretical memos and that they continue with this strategy as their memos become more complex and analytical to keep the participant's voice present in the theoretical outcome (Charmaz 1995; Charmaz 2001). Charmaz positions the researcher as a co-producer rather than making the underlying assumption that the interaction between the researcher and participants 'produces the data, and therefore the meanings that the researcher observes and defines' (Charmaz, 1995, p. 35).

She has argued that CGT practitioners feel that while it is necessary for their writing to be analytical, what is needed is that their writing style should be evocative of the participants' experiences (Charmaz, 2001). The researcher's voice need not 'transcend experience but re-envisage it … bringing fragments of fieldwork time, context and mood together in a colloquy of the author's several selves - reflecting, witnessing, wondering, accepting - all at once' (Charmaz & Mitchell, 1996, p. 299).

CGT supports my practice of observational journaling and narrative analysis, with me as the researcher and participant in a co-construction of experience and meaning. For a study to be able to be placed under the umbrella of GT it will:

1. Conduct data collection and analysis simultaneously in an iterative process.
2. Analyse actions and processes rather than themes and structures.
3. Use comparative methods.
4. Draw on data (e.g. narratives and descriptions) to develop new conceptual categories.
5. Develop inductive abstract analytic categories through systematic data analysis.

Charmaz states, 'I view actions 1–5 as evidence of a grounded theory study' (2014, p. 15). I implement these five categories in the analysis of the data in Chapter 7.

In this chapter the following methods are defined - CD uses participation and collaboration, NA works with observational journals, DVE is produced by the creation of digital canvases, and animations and video stills, BM is a visual auto-biographical story-telling technique and CGT performs data collection and analysis simultaneously in an iterative process. In chapter 4. the structure and concepts that make up the digital arts-based research workshops is introduced. A digital prototype sketch based on art works and case studies from the workshops is outlined. Guidelines for evidencing health and wellbeing for children and young people are selected and indicators of health and wellbeing are defined.

Chapter 4:

Digital prototype sketch and artworks based on case studies

A digital prototype sketch is a rough version of the research analysis and data that assists in moving towards a finished prototype and future iterations of research and development. This chapter presents a research narrative of a digital and analogue journey that explores innovative paths for the design of a health and wellbeing application that originates with digital arts-based research activities. I present samples of the visual research data made by TYA patients in the co-design workshops along with journal entries detailing this experience. The way in which the TYAs relate to digital art media, their responses to traditional art media, and their participation in the autobiographical and body mapping process are all thought through in this prototype sketch.

Many teenagers and young adults are now integrating digital devices and digital art tools within their creative expression of personal identity. These expressive arts tools are used within their desktop computers, laptop computers, tablets and smartphones in addition to the organic body and traditional art media. The digital art medium is what creates and paints the virtual digital landscape.

Using digital art media as the basis for the design of an artist designed digital art therapeutic prototype allows for the TYAs' contemporary subjectivity to be explored and consequently expressed congruently within this context. As explained by Boesel and Rey (2014):

> The contemporary subject is therefore an embodied subject whose materiality resides not in any one distinct and separate medium (organic body, conventional prosthesis, or digital prostheses), but which is performed both within and across multiple media. In order to fully understand what the implications of such an embodiment are for the contemporary subject, however, we must turn to examining the historical conditions that shape her (p. 178).

Young people today use digital technology for self-expression and in combination with traditional art media. The following three exercises yield a selection of digital media artworks and a successful visual story-telling model to begin conceptualizing what the prototype looks like.

I call this a digital prototype sketch because I consider the data organised within this chapter as a blueprint for a further iteration of this research project featured in Chapter 5.

Prototype sketch tools. The data that I present here is based on four different activities that I facilitated with the TYA patients in the co-design workshops.

- Digital animation workshop.
- Abstract auto portrait collage (AAPC) and digital collage (DC) workshop. In this mode the collage is created digitally.
- Body map using traditional art media.
- Individual body map using collage cut out from printed matter such as magazines and newspapers
- Collaborative body map.

Below I show examples of the patients' artwork based on these activities that I collected from co-design workshops that took place in 2013-15 and in 2017. I include journal entries of my impressions of working with the patients for further understanding of the research context. With this visual data I present how I have applied my findings to the digital sketch prototype tools.

Workshop structure

All of the workshops including digital art and traditional art media are based on the same structure. They happened once a week on a Monday, Tuesday, Wednesday or a Thursday from 11 am to 1pm, February 19, 2013 to July 23, 2015 with a two-year maternity break, resuming from March 9, 2017 and ending on July 9, 2017, working with an estimated total of 120 participants. Twenty-eight of the 120 participants chose not to share their data. I logged 92 (see research log in appendix) participants that included 43 female, 44 male and five gender-neutral participants. In 2013 I worked with 17 males and three females, in 2014 - 14 males and 10 females, and in 2015 nine males, 23 females and five gender-neutral. In 2017 I worked with seven females, four males and one gender-neutral participant.

The workshops took place in the Hub which is located in the TYA specialist cancer unit (see above: Research context section). The unit looks after lots of young people with different cancers who are receiving different types of treatment. The service is nurse-led care provided by specialist staff. The unit consists of day care, ambulatory care and recreation area, known as the Teenage Cancer Trust Hub. The Hub was designed and based on the suggestions of young people. It is a space for patients and families and includes a

gym, DJ booth, computer, gaming space, education zone, pool table and an arts and crafts station. The day care treatment space is open and sociable. The workshops that use the body mapping method can take place in the clinic at the bedside (see Fig. 3).

Patients can expect to wait two to three hours before starting chemotherapy on the first day (this includes oral chemotherapy). This is due to the assessments needed and the safety processes involved in delivering chemotherapy. If they are having radiotherapy, they will attend TYA day care for weekly blood tests, medical reviews or chemotherapy. It is during this time that I recruited participants.

The structure of each workshop was dependent on the location of the computers and the arts and crafts station, the number of available participants, and the amount of time the participant had to commit to the digital and traditional art exercises. The structure of the workshop was modified when traditional art media was used for the exercises at bedside. Because there were no iPads available to be used at bedside, the participant needed to be using ambulant infusion so that they could walk around wearing the chemotherapy pump to work at the computers provided in the Hub to do the digital art exercises (see Fig. 3 below). The arts and crafts table was located behind the computer station.

All workshops begun by setting up equipment and materials, participant recruitment, activity briefing and participant consent, tools demonstration, and creation of art artefact/data.

Fig. 3 (top) The Hub-1

Fig. 4 (bottom left) The Hub-2

Fig. 5 The Hub-3

Fig. 6 Chemotherapy clinic UCLH MacMillan Cancer Centre

The workshop activities are detailed in the following sections. The workshops closed by helping the participant save files and art work and getting permission to use their artwork for research data. I then journaled about the sessions. The workshops became a part of the Hub. There are art volunteers who did independent activities with the patients in addition to the activities that the play specialist presented daily at the arts and crafts table. Often there was a music therapist teaching a patient to play the guitar near the computers on the red sofa (see Fig 3).

This multi-activity environment provided an open and social background for recruiting participants. For patients and their families who appeared interested in participating in art-based research, I worked to convey what the aims of the research were and what they could expect from taking part in it. That being said, recruiting participants was still a very challenging part of the research. The patients were frequently too unwell or just did not feel like participating**.**

Recruitment of participants

My previous experience in teaching this age group helped me understand what to expect. I would promote my workshops by putting up posters that I designed (see appendix - 1) around the Hub. The play specialist included it in the weekly activities calendar that was made available to patients. She also suggested it to patients. I approached patients in the Hub or in the clinic by approaching them in a friendly manner and introducing myself.

I would ask the patients and the guardians or parents what their names were. This usually established trust that helped to motivate them to take part in the study. I would then explain that I was leading animation and digital art workshops that would be a fun activity and a good way to pass the time and learn something new while waiting to be called for their appointment or passing time while receiving chemotherapy in the clinic. I would show them a participant information leaflet (PIL) about what to expect from participating in the activity (see Appendix - 1 for PIL). I attempted to reinforce to the parent or guardian that this was a positive experience, so I would assure them that there was no pressure to participate and that they could stop at any time if they felt that it was not for them.

The youth coordinator liked me to go around the beds and ask the patients who were receiving chemotherapy if they were interested in participating. At first, I found this the hardest thing to do. The young people looked very tired and weak, more often than not they had lost their hair. Their parents consistently looked very worried. The young people usually perked up when I offered the workshops, and normally one or two to came to participate while they were still having chemotherapy.

It was important that the participants knew that it was entirely acceptable not to want to be involved. At first when a patient declined my invitation, it was difficult for me. I quickly learned to formulate a way to cheerfully say that it was alright with me and that there was no pressure on them. I would let them know that I was across the way at the island of computers if they changed their mind and wanted to participate. I turned it into a way of giving them an option of something to do if they wanted to. I offered the same opportunity to caregivers, parents and the siblings of the patients.

When I began temping as a Youth Support Co-Ordinator at UCLH, I was given a new badge from NHS temp agency Bank that had my picture and my position as a Youth Support Co-ordinator. This allowed me to blend in more easily. The relationships with the patients began to feel less artificial to me. I found that the patients were now seeking me out for

activities and for support and someone to talk to. The next sections show samples of visual data and narrative data and how it was generated within the workshop structure.

Guidelines for evidencing health and wellbeing in the workshops

The following sections provide evidence that serves to answer my research questions: What does this data tell us about the ways that we can evidence that digital animation and digital arts promote health and wellbeing? What does the digital in arts-based interventions allow us to measure and evidence that we were unable to before?

To answer these questions, it is necessary to provide the guidelines that I used to make these assessments. As an art for health practitioner and art practice-based researcher, I am basing my health and wellbeing conclusions on two different frameworks; first, the three dimensions of wellbeing, as outlined in What Works for Wellbeing and Sport (Daykin et al., 2016):

- Personal dimension: includes confidence and self-esteem, meaning and purpose, reduced anxiety and increased optimism.
- Cultural dimension: includes coping and resilience, capability and achievement, personal identity, creative skills and expression and life skills such as employability.
- Social dimension: includes belonging and identity, sociability and new connections, bonding and social capital, reducing social inequalities and reciprocity.

These dimensions can be applied to children, adolescents and young adults as well as adults. To contextualise the arts in health dimensions of health wellbeing within the TYA study group I cross-referenced these standards with the eight Getting it Right for Every Child (GIRFEC) indicators of wellbeing for children and young people (Scottish Government, 2018) that are cited below. Young people are considered to be ages 5-18. Ages 19-24 fall within the category of young adult, this being a transitioning stage to adulthood which can be evaluated by the same standards as the general health and wellbeing dimensions outlined by Daykin et al. previously. I used these different standards in recognition of the potential vulnerability and the particular differences between TYAs ages (14-24) and other people at different stages of age development, for example an older adulthood group or an end of life group.

There is an overlap between the age groups of children, young people and TYAs, and those of adolescents and young adults (AYAs) (RCP, 2015), who are ages 16-24. AYAs represent the transition that young people make into adult services, and it is in this space that they can become lost in the system. This has been described by NHS England and others as a 'cliff edge' (APPG, 2017, p. 96). It is this group that can most benefit from the attention paid to their health and wellbeing needs through this research and the outcomes.

Because of the overlap in age groups and the limits at which adolescents and young adults are categorised as such in the medicalised environment, there are no clear guidelines for the health and wellbeing indicators for the transitioning period from young person to young adult. That being said I extended the indicators of health and wellbeing for young people to include young adults. To do this I used the understanding of wellbeing outlined by GIRFEC as described in terms of eight indicators that are commonly referred to by their initial letters, SHANARRI (Scottish Government, 2018).

The eight indicators of health and wellbeing for children and young people are:

Safe- Protected from abuse, neglect or harm at home, at school and in the community.

Healthy- Having the highest attainable standards of physical and mental health, access to suitable healthcare and support in learning to make healthy, safe choices.

Achieving- Being supported and guided in learning and in the development of skills, confidence and self-esteem, at home, at school and in the community.

Nurtured- Having a nurturing place to live in a family setting, with additional help if needed, or where possible, in a suitable care setting.

Active- Having opportunities to take part in activities such as play, recreation and sport, which contribute to healthy growth and development, at home, at school and in the community.

Respected- Having the opportunity, along with carers, to be heard and involved in decisions that affect them.

Responsible- Having opportunities and encouragement to play active and responsible roles at home, at school and in the community, and where necessary, having appropriate guidance and supervision, and being involved in decisions that affect them.

Included- Having helped to overcome social, educational, physical and economic inequalities, and being accepted as part of the community in which they live and learn.

GIRFEC states that the indicators make it easier for everyone to be consistent in how they consider the quality of a child's or young person's life at a particular point in time. They assert that each child or young person is unique and there is no set level of wellbeing that children and young people should achieve and that each child and young person should be helped to reach their full potential as an individual (Scottish Government, 2018).

The proceeding activities with the TYAs using the computer and digital tools served as evaluative measures to explore the advantages and disadvantages of probing identity and auto-portraiture with digital art media. Health and wellbeing are evidenced in the journal entries that correspond to the featured digital art artefacts in the following sections. I do this by comparing the indicators and dimensions of wellbeing with coresponding qualities in the visual data and journals.

Digital Workshops

Flash animation workshops

This animation software can be used in combination with other art activities. At the hospital there were four computers with Flash installed. I had been leading the workshops using the free 40-day trial and when it ran out the play specialist purchased the software after seeing that the patients were interested in learning with it. For hygiene reasons, the computers had flat stainless-steel keyboards, which can be disinfected easily, but are not easy to type on. I was required to clean them with anti-bacterial wipes before each session. One of the most common complaints from the participants was that the keyboards were difficult to use because you need to press very hard on the keys to get results.

I negotiated with the hospital to purchase computer mice to draw with and mouse pads as well as Wacom touchpads. I sat next to the participant so I could first demonstrate from my screen. If there was more than one participant, I sat behind them to instruct them

on how to operate the interface. I would ask the participant questions such as: “have you ever used graphic arts programmes before?”; “do you like to make art with computers?”; “what kind of computer art programmes have you used before?”. Through these questions and the answers that they provided I was able to assess their experience level. See below for an example of one of these encounters, detailed in a journal entry:

April 9, 2013

Participant A. is a 20-year-old woman who is having her first chemo treatments. Annika took me to the treatment room where about six others were having treatment. She had a side table that we could draw on. I asked her if she likes to draw. She said she did when she was little. She said that she likes doing activities on the computer like Facebook and texting on her phone. She remembered that she had done some graffiti-type text on clothing in a workshop when she was young. She said that that that style is not in fashion anymore. So, she began to write her name in bubble letters and remembered her nicknames ‘Little One’ and ‘Baby Gurl’ and ‘Princess’. She covered a page writing these nicknames in different styles. Although I did not get to work on computer animations with her this day, her response that she likes to do things on the computer indicates that digital art programmes can be an appropriate mode to reach her in a therapeutic sense.

Frequently there were participants who were studying graphic design or computer science and we are able to have advanced conversations about computers or animation. For example, in this journal entry:

November 25, 2013

Today Annika was not in again. I felt a little bit sensitive today. There was a woman in the elevator pushing her daughter in a wheelchair. They were going up to the Hub and I thought I recognised the girl, I think that it was Bella, the girl I wrote about a few months back, but she had deteriorated in an unrecognisable way. I located the computer mice and set up the computers. I went to the bedsides and Participant B was there and said he would come over and do some animations. I talked to him last week and he said he would be up for it. He was a very sweet boy he is from Essex. We talked about accents and he remarked on mine. He asked me where I was from. “San Francisco,” I said. I showed him the bouncing ball exercise and he caught on very quickly. Our conversation meandered through politics, Obama and how annoying the crumpet-eating uptight British types are. We ended with a conversation

about skateboarding and he said he wished he could ride a skateboard. He said his sister is in L.A. for a few months and that she rides a skateboard. He ended with a drawing of a muscley guy riding a skateboard. His chemo drip beeped; it was time for him to go back and check on it. He said he would come back, but he did not. So, I cleaned up the art table and wiped it down with the cleansing wipes that they have around. Then came in Z, he is a youngish man who is another play specialist like Annika. I was really in need of some conversation, so I began to talk his ear off. He was quite supportive of what I was doing with the computer arts. He believes it to be a good thing. I asked him how he arrived at his job. He said that he had previously worked in the community with young offenders and at-risk groups of young people. He is a nice guy. I may approach him about some co-design activities. I have a sense that he could be very helpful.

Then a young man called S came in to do some animations. He was quiet and smart. His parents said that he was a techie. He quietly listened to me and then began to make a stick figure with a bow and arrow that shot through an apple that he downloaded from the internet. It was quite good. We sat quietly and worked together for almost an hour. At the end he put his swf in Dropbox. He began to tell me about a project he is doing at school where he is building his own computer from scratch. He showed me a list of all the parts that he had to source out at a budget of £200; he went over budget by £136. He had a spreadsheet with the list of the components and a column to put the prices of the items to add it up. He said he was going to complete the computer in two weeks. We talked about Photoshop. He said he was considering getting Creative Suite to put on his new computer that he made himself. I said, “great idea!” I emphasised how great photoshop is to make art with. I was very impressed with him. I guess we are all really travellers meeting each other along the way. I feel that I met a very special traveller today. I hope that his excitement about computing and digital art will create a path to recovery for him. I believe that art can heal. Digital art and computer art have the same potential as traditional art materials; I believe even more so for this young generation.

I started by giving the participant a tour of the tools box. Cartoons are useful to introduce to the participants while making animations. I asked them to think of the stage, the white rectangle that you animate on, as a theatre stage. The grey area surrounding the stage is the wings of the stage. This creates a sense of play and imagination. If the participant was an absolute beginner, I started them off with the bouncing ball exercise (see Fig. 7). This exercise is easily learned and can provide results within about 15 minutes. It

takes the participant through the process of creating a simple bouncing ball animation, which allows you to study the way objects manoeuvre in the material world. This knowledge can be applied to any shape or object to make it appear as though it is moving with the same laws of physics of the organic world. In this exercise the principal of timing and spacing is emphasised as these two things are vital to animation. If I had more time with the participant, I encouraged them to create a scenario that they wished to animate. I found that introducing the ball exercise usually led them to make animations that included the ball; for example, stick figures playing catch with the ball, or a stick figure scoring a goal in football.

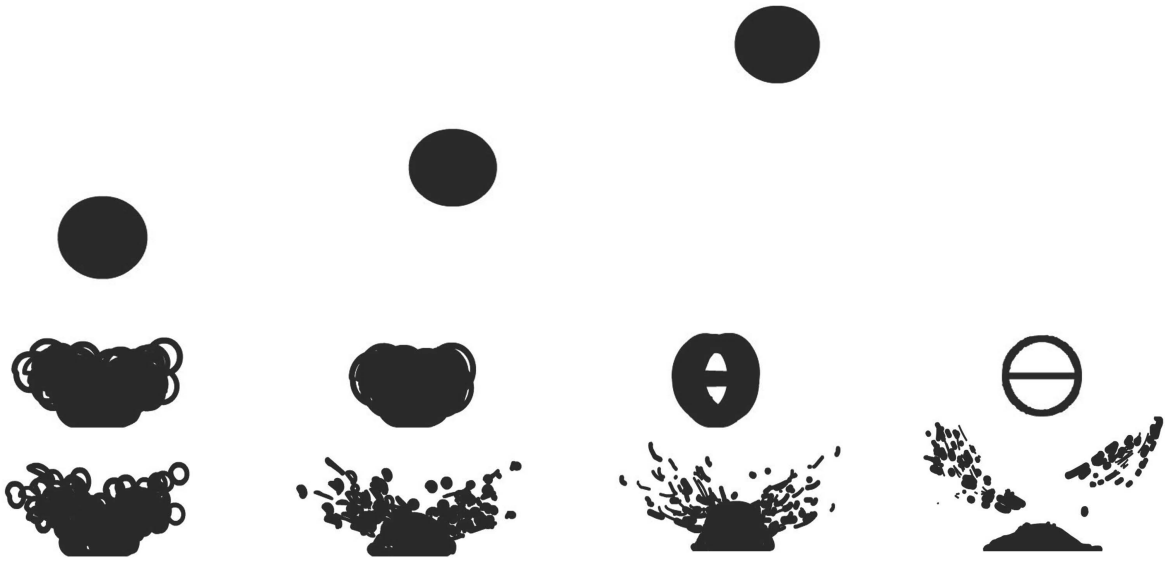


Fig. 7 Bouncing black ball

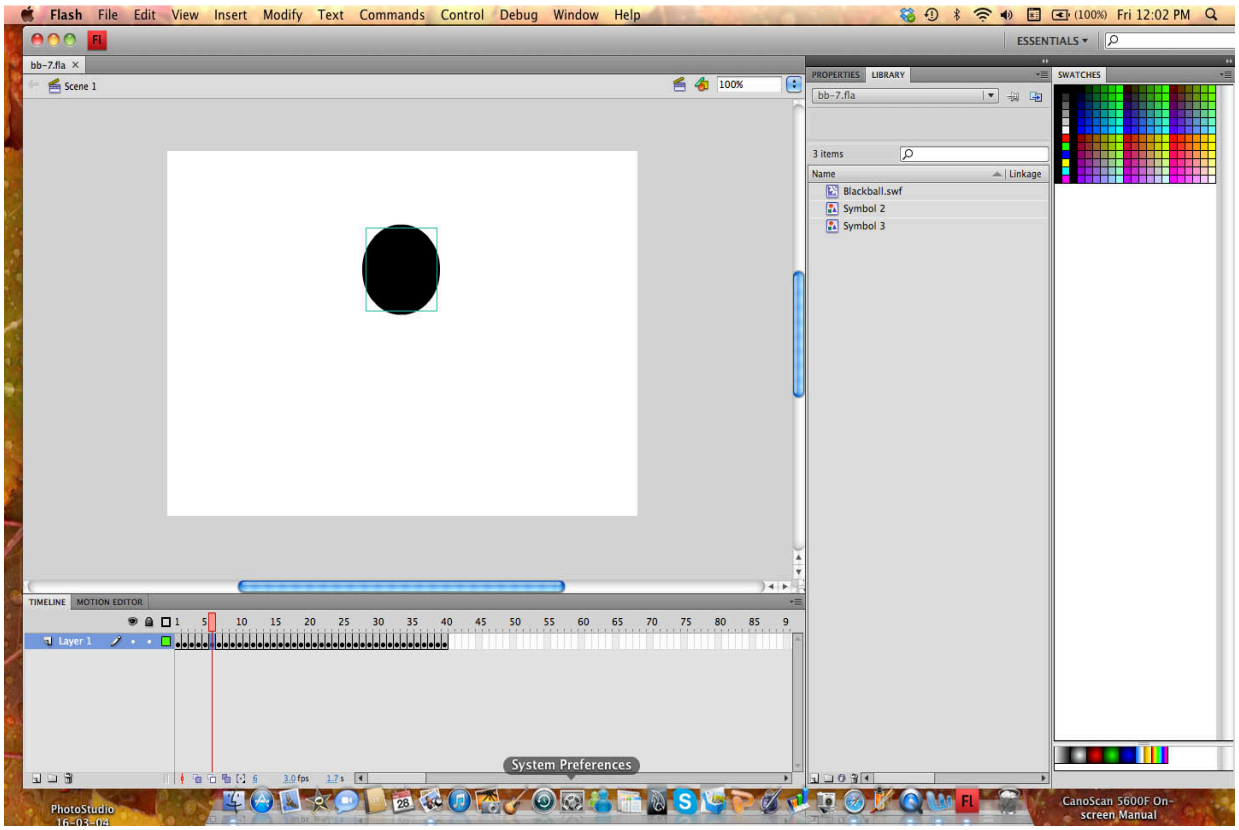


Fig. 8 Flash animation screenshots from UCLH workshop (2013).

If there was time, I introduced importing images to the stage from the internet. This process creates a collage effect.

Throughout the session, I kept asking questions about which tools they liked best. These questions helped inform my journaling process. I found that by showing them a few simple techniques and getting them started off, they began to make their own animations and asked me how to do more advanced operations. Then, I was able to help them achieve the results that they were looking for.

This process created a space in which the participant felt free to communicate what was happening in the moment through the moving image. I could see that learning a new skill and having such immediate results added to their self-esteem and a general sense of well-being. The following journal entry illustrates my observations of a participant doing a bouncing ball exercise. This exercise can lead the participant to expand on the theme of the ball in order to create something new and original.

Narrative enquiry: journal entry

February 19, 2013

Today was my first day trying out the animation workshop at UCLH Macmillan Cancer Centre in the Hub on the teenage and young adult floor. The patients are aged 13-24. There is an island of six PCs. Four of them have the free 30-day trial of Flash loaded onto them. I worked with Participant C who was accompanied by his father. C was around 10 or 11. He has begun to lose his hair. He was in the process of having chemo when he sat down to the computer. I showed him how the timeline on Flash worked and the most basic exercise, the bouncing ball. Through a process akin to a flipbook, you make the ball move and squash and stretch when the ball reaches the ground, so you achieve a sense of gravity.

Like most digital natives, Participant C got it instantly and he was off and running and drawing his own images that moved convincingly into the next image. After he achieved the ball exercise, he made the ball explode into smaller balls that descended to the bottom of the stage. From those balls rose a hand-like image that then caught fire. From there he drew a red rocket that travelled from the left side of the stage to the right, aiming at the flaming hand and hitting it. Patient C was quite focused on what he was doing and was sitting quite still, with the exception of moving the mouse. There were two nurses with him supporting him and cheering him on. The animation loop plays for about a minute. I saved the open file and the swf file to the desktop so he can return to it when he returns for the next round of chemo.

I see these animations/moving images as a stream of consciousness not to be analysed in a psychoanalytical sense but as images to be curious about. The process of interacting and learning how to do something, then to be able to see it on a screen almost instantly is therapeutic. As I journal my observations, I understand what it is that I am trying to achieve by leading these digital art workshops. I am simultaneously learning and teaching a new language. The user interface (UI) is the meeting point for co-creation, improvisation and the performance of visual language. Participant C was using ambulant infusion hooked up on a tall metal rack that has wheels for mobility. He wanted to participate and appeared to be interested and engaged in the activity. He managed to work with the equipment that was available, though it was not the most ergonomic or comfortable way for a person having chemo to make art. He did not complain even though he had a peripherally inserted central catheter (PICC) line in the large vein above the bend of his elbow.

Fig. 9 Participant B Flash animation workshop, male 10-11 years old (2013).

This journal entry evidences wellbeing in that the participant exhibits the GIRFEC indicators of being active, being included and achieving in the workshop activity. The nurses cheering him on reflect him being included. Instead of reclining while having chemotherapy he made the choice to participate and be active through learning and making. He achieved the task of making the ball bounce and furthering his narrative with his expressive explosions. When I asked the patients if it would be too painful to draw in the computer with

the PICC line in they always said no. While leading the workshops I was able to ask them questions such as “Does it hurt to use the mouse while having chemotherapy?”. The participants did not say that the IVs that were inserted in their arms affected their ability to use the keyboard or the mouse. The participants who were mobile appeared to adapt and persevere.

The TYA patients exhibited resilience; their willingness to extend themselves to participate in this study even though it may not have been comfortable made a strong impression on me. One participant mentioned to me that the artwork he was making in the workshop was taking a lot of emotional energy. I asked him why and he said because the painting is like his baby and he wants it to be perfect. I said to him it did not have to be perfect. He then said “yes, it does, because I want him to succeed.”

This dimension of emotional energy is one that I had not previously considered. I learned from the participants what it is that they needed. Ergonomics and comfort during digital art workshops is another rich area of research to be pursued. Because the participants did not complain of pain while using the computers, for this specific study I have focused only on the human-computer interaction using the computers for digital art that are available in the hospital.

Fig. 10 Bee and face by Participant C. Modelled on Adobe Flash Pro (2013).

Site writing

Below is a sample of the method site writing that I set out in chapter 2.

October 22, 2013

I worked with a 19-year-old man from Afghanistan (Participant D). He was doing well. He had had a hip replacement because the cancer was around that region. His hair was growing back but he showed me that it was still thin. He had shaved it a couple times so that it would grow back thicker. He was very friendly and agreed to sit down and try to make some animations. He said he was very good at cell phones, and Facebook. When he found out it was an art-making programme he began to protest. He whinged, saying "I'm rubbish at art." To his credit, he scribbled a few things.

We started talking about what he was going to do when he recovered because he said all of his original plans to be a bricklayer, a plumber, or anything that involved using his leg a lot was out. I said, "well, you are going to have to use your mind then." He said one of his friends did IT and that maybe he might give that a try. He told me that he does not have any family here and that he came over five years ago. He had a really good attitude and he looks quite healthy. He said that he has some people that are like family that support him in Kent.

I Googled an adult education centre in Kent and we looked at possible computer courses he could take. He showed general anxiety at the idea of taking a computer class. He said he is not good at book learning. I stayed with him and encouraged him to look at some of the courses. He then said he would like to perhaps study business. He said he would like to open up a kebab shop and that he was good at and comfortable with cooking.

I asked him a little more about how he came to England, he said it was because there is/was trouble in Afghanistan. I noticed how white his teeth were and I wondered if they were dentures. He made me feel hopeful about the cancer treatments because he has been through so much and he looks so well and appears to be recovering.

Annika said he is probably a refugee. I went around to do the rounds at the beds where the patients were receiving chemo and let them know I was over at the computers if they wanted to join in the workshop. Two of them were just beginning their treatment.

There was a boy that I worked with on another day on the other side with his chemo drip attached. His father was sitting with him. He was sitting with his laptop open. I was not able to see the screen, so I do not know what he was doing, working or playing. He was much younger than all the others. He said he would join in on another day.
Annika asked me to make stills of some of the animations and send them to her via e-mail so she could display them on the wall to exhibit what the workshops are about. My observations are that personal technology is part of the treatment and recovery process. Most clients are using a computer or handheld device for most of the time during treatment and while in the process of waiting.

I see a gap here for offering interactive therapeutic digital mediums. Perhaps even prescriptive activities that can enhance rehabilitation and keep the mind active in a positive, even mindful, way.

There are points or nodes where the technology creates a barrier to the art-making process. The technology is geared for the expert or the designer, which creates an inequality through privileged language forms. I notice some people are intimidated yet cell phones or Facebook do not intimidate them. There is something to be learned from the computer interface of Facebook and their populist design. It welcomes everyone.

I can see that those who do not adapt to the software that I am proposing will be excluded from the project. In a way Facebook encourages technological ignorance. It is a different language that they are utilising. This language does not afford any learning of new

technologies that could benefit young people in the workplace or encourage an art therapeutic practice.

In this site writing it is becoming clear to me the disadvantages and limitations of using off-the-shelf applications with the TYA participants. The computer was proving to be a way to communicate with the TYAs. They would engage with it during the workshops, talk about applications at different stages of computer literacy. I have found through this study that computer technology and computer-generated images are enablers of communication and storytelling. I have observed that the computer and new applications can also cause insecurity, stress and anxiety surrounding issues of literacy and accessibility. This is evidenced in the previous journal entry with the young man from Afghanistan who was anxious about the concept of taking a computer class and engaging with digital art. The young man who explained that the digital art exercise demanded too much emotional energy and caused him to adopt a perfectionist attitude towards the outcome of his artwork demonstrates stress and anxiety in the participant.

In the next journal entry are examples of the excitement some of the participants experienced through working and playing with Flash animation. The participants visibly display an elevation in mood when they are working well with the digital art applications. This indicates increased health and well-being. The Animation Project TAP (Austin, 2018) and The Re-animation approach (Mason, 2011) also cite the health and wellbeing benefits of animation.

Journal entry

March 31, 2014

Today I worked with a boy called E and a young man, F. E, was there to see a psychologist. It was E's first time being at the cancer centre. He was keen to try something new and make some animations. I started out with the bouncing ball exercise. He caught on quickly and listened well. He liked the idea of importing images from the internet to use in his animation instead of drawing his own character. I find this interesting because the items that the patients choose give insight into what they are interested in. He chose an image of a night elf from the game *Warcraft*. He specifically searched for a jumping night elf. The other image he searched for was an Orc, which is a kind of troll or monster creature, also from the *Warcraft* series. He then placed them at opposite sides of the stage and asked me how to make an arrow. I showed him some different tools and he said, "I know what I can do!" and he managed to make an arrow on his own. Then the psychologist came to get him for his appointment. I noticed that the psychologist took note that S was engaged in making art and he asked if he could take a cup full of pens from the communal art table.

Next, I worked with F. I met him a few weeks ago and he was not feeling well. He was excited to make animations. He had a thick African accent that was challenging for me to understand. His leg was injured from taking steroids and it appeared to be bothering him. I started out with the bouncing ball exercise. This I believe made him think about basketball. He asked me where I was from. He said he would like to go to Oklahoma because that is where his favourite team is from. He mentioned that he is a glory hunter and that he just likes to support the teams who are winning. He was amazed at what he could do in such a short space of time. His reactions to seeing his ball bounce across the screen reminded me of myself and how I felt the first time I used Flash and was able to make things move.

He actually said, "this is amazing" and he said he wanted to learn something else. He said he wanted to draw a human holding a water bucket and have him bouncing across the screen. His figure was drawn in green with the paintbrush and had thicker arms and a square head. The bucket was an extension from his arm also in the same green. He filled the bucket with blue paint for water. I showed him how to select the entire figure and he used what he learned to make the figure bounce across the screen. He was very amused by his work. He said that he had never seen anything like this. He wanted to know if he could download Flash onto his computer because he was staying in the wards and wanted to practise on his computer while he was back in the wards.

I showed him how to get to the Adobe website to download the free 40- day trial. He was very eager to learn something else, so I had just enough time to open up Adobe Photoshop Elements. He said that he had never heard of it before. I had just enough time to show him how to open an image and alter it by erasing and painting on top of the layers. He asked me if he could create a certain kind of image that was hard for him to explain. I encouraged him to try to explain. He began to show me that he wanted to make some of the images transparent with some other images in layers. I said yes you can make an image like that. Then a nurse came to take his fluids.

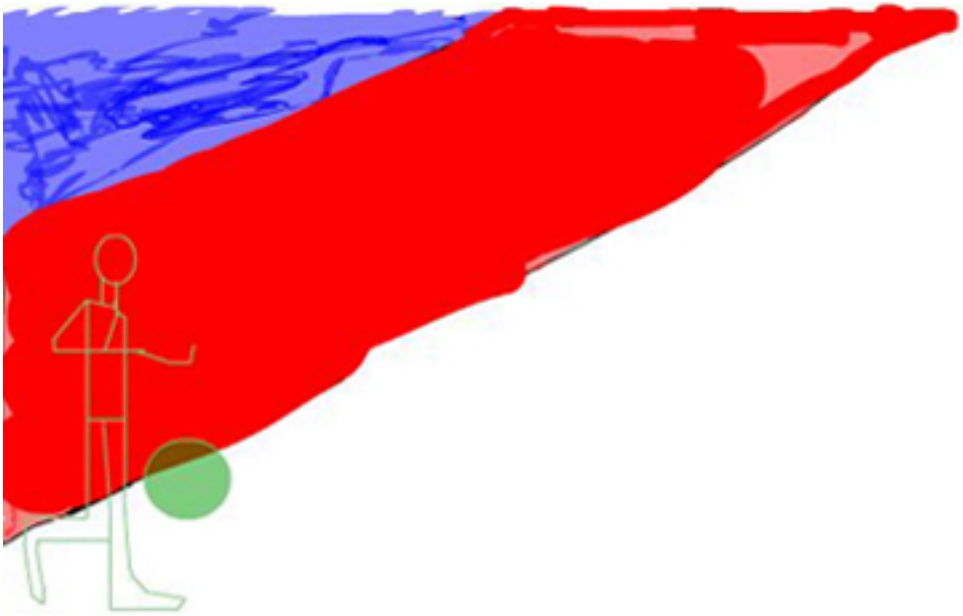


Fig. 11 Flash animation screenshot from UCLH workshop (2013).

Fig. 12 Flash animation screenshot from UCLH workshop (2013).

The previous journal entry evidences wellbeing through the participant being active, achieving, and included through the acquisition of creative skills and through expression. The dimensions of confidence and self-esteem and increased optimism is evidenced through participant T when he expressed amazement at what he could achieve in a short period of time and his enthusiasm to learn more.

Through the narrative analysis that focused on the participants stories and the observations in the animation journaling I take away a few key points. I address my research questions: what does this data tell us about the ways that we can evidence digital animation and digital arts promote health and wellbeing? what does the 'digital' in arts-based interventions allow us to measure and evidence that we were unable to before?

Key points

1. The TYAs exhibited familiarity with digital interactive technology. Many of the participants that I worked with had previous experience with and used either computers, smartphones, and/or tablets regularly.

2. The TYAs and parents or carers were willing to participate in digital animation activities while having chemotherapy and while waiting in the ambulant care clinic for various medical treatments.

3. The moving image had a positive impact on the TYAs' optimism and was effective in the formation of a visual language for the prototype sketch. It is possible that introducing the moving image to static digital art interventions and the prototype sketch can produce health and wellbeing qualities such as optimism.

The animation stills and the journal entries combined evidence that digital animation promotes health and wellbeing through being active, social inclusion, increased optimism, acquisition of creative skills and expression, and a sense of capability and achievement.

When the perception of the computer shifts from a machine to do work on to a machine to make art with, it begins to embody the capability to promote health and wellbeing as effectively as traditional art materials with added affordances that DAT provide (Garner, 2017; Malchilodi, 2018; APPG, 2017). This is imperative in the lives of this study group of TYAs who have grown up in a context where computers and digital media are common and embedded in the everyday world. Many of the participants were attracted by the digital media and would not have participated if they were offered traditional art media. Digital media offers a space where health and wellbeing can be improved for people who do not relate to traditional art media in addition to those that relate to both.

The 'digital' in arts-based intervention allows for the measurement of how digital art tools function through recording research activity, with the media being used for art production in real time, the recording being a Flash animation video or a digital file in j-peg format that can be used for comparative analysis with traditional art media. Digital art software can archive and reproduce the participants' artwork at every stage of the activity.

The digital art artefacts can be produced, analysed and archived digitally within the computer.

The 'digital' in arts-based interventions allows for digital multimedia art data and traditional art data to co-exist in a virtual world that can be examined and explored. The digital animation workshop series showed that digital animation technology has limitations, but these were not significant enough to discontinue this research. More data and analysis can be found in the evaluation (Chapter 5).

After working with animation for a year I decided to use a new research activity that was prescriptive and followed a set of simple guidelines. My intent was to present an exercise that would be specific so that I could collect many examples from individuals to do comparative analysis. I used Adobe Photoshop Elements to do this. In the following section I present the second iteration of the digital arts workshop.

Abstract auto-portrait collage (AAPC)

The AAPC begins with a collection of images that the participant harvests from the internet that they feel represent their personal qualities. I asked them to choose three images to work with. The participant then creates a composition with digital tools in Adobe Photoshop Elements to construct an abstract interpretation of themselves.

This is achieved by altering the images through cutting, rearranging, painting, layering and novel filters that are available in the application. The activity encourages the participant to think about identity in unusual ways, such as across different media platforms, as expressed previously by Boesel and Rey (2014). In this exercise participants can meditate on multiple aspects of themselves and have the freedom to express those aspects in any visual way within the limits of the computer's art-making software.

The AAPC generated dialogue and completed art works. These art works gave the participant a way to describe and talk about personal attributes and life experiences. The process that they talked about when working on the AAPC tended to be non-linear. They drew from different temporalities and subjectivities to create their AAPC.

The AAPC was a way for the participant to think about their inner world and what they can attach visually to personal traits and meaningful life experiences. The AAPC is a self-reflective tool for externalising a person's interior reality. For some participants the AAPC was an opportunity to talk about their lives and for others it was an amusing activity to see

their images and how they could be manipulated. In many cases humour is used in the juxtaposition of images as evidenced in the following journal entry and image.

Journal entry of making a Photoshop Elements collage with Patient G.

July 28, 2014

I approached Participant G and his father/caregiver to make a Photoshop Elements collage. I found out that G is from Spain and speaks Spanish. His caregiver speaks Spanish as well. We all sat together at the computers while making the collage. A chose to use the images that other patients had selected and archived in a folder called 'Abstract auto-portrait collage'. He chose an image of a landscape with a mountain on it for the background, a giraffe on whose face he placed black Ray Ban sunglasses, and a caricature of a popular footballer. He cut these out with the editing tools and pasted them to make a collage. He wanted to search for another image on Google and he could not think of the word in English that he wanted to find. My Spanish is not good enough to translate. He typed some words in the browser and searched for images. People hanging themselves and images of suicide appeared on the screen. I turned to his caregiver and asked him if G was okay and if he needed someone to talk to. He said that G was looking for a funny, humorous kind of image and that he was okay. I suggested the word 'comic' for a search. A typed in 'comic' and began to choose an image. I pointed to the Incredible Hulk and to word bubbles that said things like 'Boom!' and 'Pow!' He carefully selected a retro cartoon of a catlike creature that appeared as though it was jumping with a boy character that looked as though he was also jumping with text next to him that I cannot recall precisely. G placed the jumping characters on top of the mountain and cut them out so that it looks as though they were jumping off the mountain.

The journal entry evidences that the AAPC promotes activity, creative skills expression and achievement. By choosing to participate, G was active. He wanted to find a humorous image, so he created one of a giraffe wearing black sunglasses. He was able to express himself and at the same time acquire creative skills. He achieved the completion of a digital canvas.

In this case, because participant G was previously searching for worrisome images such as suicide, I notified the play specialist and she then asked me to speak to the psychotherapist about A's AAPC. I did write to the psychotherapist and sent her this journal

entry. As part of my hospital training, I had been asked to notify professionals on the ward if I had any concerns about a patient.

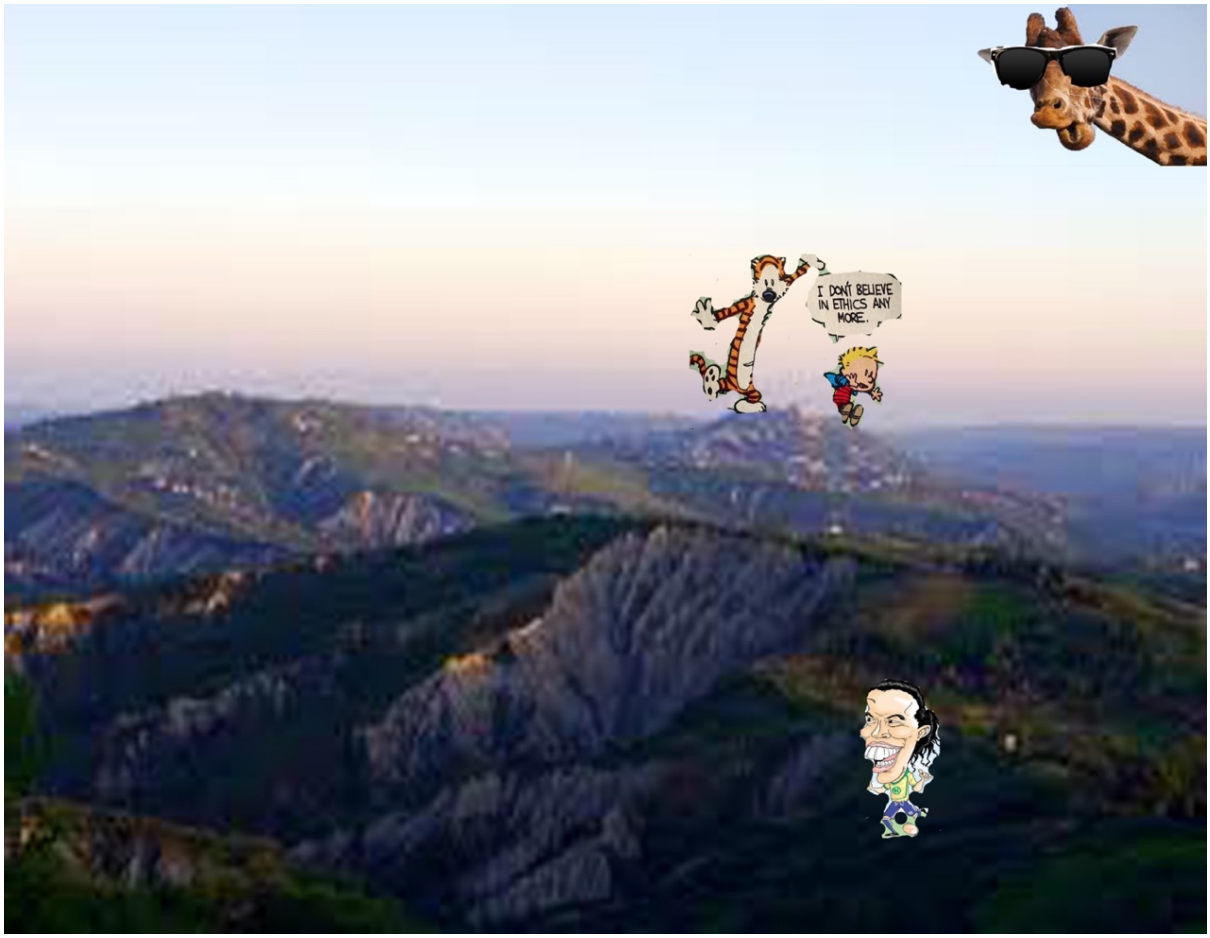


Fig. 13 Participant G. AAPC (2014).

Fig. 14 Participant G. AAPC - detail (2014).

One participant found working with Photoshop Elements too hard as evidenced in a section from a journal entry.

March 10, 2014

I helped Participant E with AAPC. She chose an image of the band Green Day, and two other bands I did not recognise. She saved them in a folder with some other images. There was one of two hands holding their fingers in the shape of a heart with a sunset in the background. She chose that one and wanted to erase behind the figures to reveal the heart shape behind them. I set her up erasing the background though she became easily distracted and began asking me questions, like “how old are you?”. Then she told me she was almost twenty and wanted to know how old she looked. Then she complained that it was too hard and wanted me to take her back to parents. She wanted me to hold her arm.

Fig. 15 Green Day AAPC (2014).

The following journal entry describes the process of two young girls who are a sibling and a cousin of a chemotherapy patient and a young man who is a cancer patient.

June 8, 2014

Today was a good day in the Hub. There were two young girls that were eager to try Photoshop and a young man who was a bit more challenging but wanted to give animation a try. The girls were cousins. The older one, Participant I, and the younger one, Participant J, were waiting for Participant I's sister to finish with her chemotherapy. The young man was busy playing a video game. His brother, who was playing pool, kept coming around trying to encourage him to try something new and make some art. Participants I and J were busy searching the net for pictures of Yorkie dogs to put in their abstract self-portraits. They successfully placed the images in the Photoshop interface and cut the dogs out with erasers and magic wand tools. Participant I put her dog on a beach because her real dog likes to play on the beach. She picked a tropical blue water scene with a long pathway stretching out to a hut in the distance. She put the dog on the path. Participant J put her dog in a park and proceeded to search for images of people and found a woman lounging on the grass reading a book. Participant I found a dolphin jumping out of the water to add to her collage. They were both sticking to a realistic theme. Slowly abstract imagination began to emerge. After sourcing two dogs running with sticks Participant J decided to put an angel hovering in the air. Participant I sourced a black boat that had been created by a designer for an art collector. The two pictures slowly took on surreal effects.

Fig. 16 Participant I. AAPC (2014).

Fig. 17 Participant J. AAPC (2014).

The above-mentioned AAPC displayed the indicators of health and wellbeing through the participants being active, respected, included, achieving, and capable and through the acquisition of creative skills and self-expression. The two young girls chose to be active through participation and achieved by learning new creative skills. They expressed different aspects of themselves and were able to share personal narratives about their dogs and experiences that were comforting to them. They showed that they were capable of using the computer to make digital art and were they respected in the clinical environment. The AAPC above were made by family members of a cancer patient. For healthy people arts engagement contributes to the attainment and maintenance of wellbeing which is much needed while they are supporting those who are undergoing cancer treatment.

The combining of photographs and cartoonish figures is an effect that can be easily achieved in the computer. This blending of reality and the imaginary is accessible to the maker and presents novel ways of thinking about personal mind states.

Many art therapists feel put off by digital art therapy as mentioned on p.26, because of lack of training in digital media, cost of equipment and the perceived insensitivities of the medium compared to the tactile experience of traditional art media (Asawa, 2009; Orr,

2012; Parker-Bell, 1999; Peterson, Stovall and Elkins, 2005). I have found that digital media has the power to mesh characteristics of the traditional to update the tools in a contemporary way within the computer or digital device in innovative ways.

The selections that the participants made that represented themselves were made into digital objects by cutting them out, painting on them or adjusting opacity and layering them. These objects have their own unique materiality that can be as transformative to work with as tactile traditional art media.

A professor of cognitive science at University of California San Diego, Edwin Hutchins, asserts that:

> for designers and many other creatives, a key part of early training is the acknowledgement and understanding that objects act as tactile interfaces as "material anchors" that can be linked to thought processes (Hutchins, 2005, cited in Day Fraser, 2017, p. 4).

Helene Day Fraser, associate professor at Emily Carr University of Art and Design in Vancouver, Canada, further articulates that:

> for the Designer considering the end-user's needs, it opens up context of use and facilitates the design of things not purely as objects or functional tools but rather things as thinking tools that may act to anchor someone, hold a memory, move an individual through a difficult time (Pasztory, 2005; Turkle, 2011; cited in Day Fraser, 2017, p. 3).

The digital object itself on the screen may not be tactile though it is accessed through a series of tactile actions. Turning on the computer, touching the keypads and manoeuvring the mouse or touchpad all enable the user to connect and manipulate the digital object and make it perform. The ability to create digital images and move them within the computer becomes a powerful and empowering experience for the patient.

As participants actively assign their own meaning to the digital objects that they are working with, personal visual narratives unfold. These narratives can be evidenced in AAPC examples in the evaluation in Chapter 5. There is the same potential to anchor a thought process and meaning to a digital material anchor as there is to a tactile material anchor. It is the thought processes that are important in the AAPC and can promote self-awareness, which is an important factor that promotes wellbeing. One of the findings of the Cultural Value Project that examined the value of arts and culture, was that the arts at once provide engagement and aesthetic detachment, enabling individuals to become more reflective (Crossick & Kaszynska, 2016). Professor Crossick states: 'One of the most important things

about health is self-reflection and empowerment and a sense that you can actually control what is damaging your health'. This sense of mastery over one's environment leads to enhancements in health and wellbeing through a process of health creation (AAPG, 2017, p. 20). The format of the AAPC leads the participant to be self-aware and reflective about their current state as well as re-visiting memorable times through the digital objects that they craft. How they assign meaning, whether it be literal or abstract, is entirely up to the participant.

I observed a sense of playfulness emerging from the participants with their portraits as described in the previous journal entry of June 8, 2014 where participant I chose an image of her dog and placed it on a beach because her dog likes to play on the beach. The beach is a sunny warm place, in contrast to the clinical atmosphere of the hospital. The AAPC becomes a place of make-believe where play and family pets exist. These positive images contribute to increased optimism for the family members that can then have positive effects on the family member who is a cancer patient. When a family member or carer is in good spirits they can uplift and motivate the cancer patient to view their recovery in positive terms. The cancer patient can benefit from having people who have a positive attitude around them.

The participant is in control of her images and how much or how little she chooses to share about them. The images can hold personal memories and emotions in a safe place within the boundaries of their digital composition. Within this composition the participant can edit and transform their identity metaphorically with the many features that digital art tools offer.

Body mapping workshop

What was revealed from working in the mode laid out above informed the next activity to do with the TYAs. What is evident from the AAPC samples included in this chapter and also in the evaluation is that the exercise encourages the participant to represent the self in concepts and thought processes. Therefore, the body is not present in these collages. In contrast to abstraction methods using digital art, I concluded that it would be beneficial for the research for the TYAs to have the opportunity to explore an organic embodied approach to auto-portraiture with traditional art media.

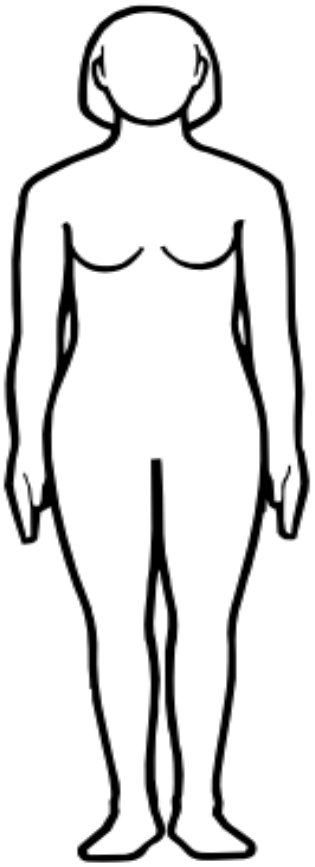
This came about from observing the participants receiving cancer treatment and the conversations they would have with me about it and what was happening to their bodies. It

became evident in the AAPC that the participants were not including these experiences in their AAPC. The patients' bodies are subject to medical processes performed by nurses and explained by them through pathological terminologies. My aim was to find a way for the TYAs to tell the story of their own body independently from the data generated by the medicalised experience. The progression of the AAPC was to extend the focus of auto-portraiture to include the body. To do this I used the body mapping the visual autobiographical storytelling method as outlined in the methodology (see Chapter 1).

In this clinical context I decided to work with minimal materials and to make the research activity as achievable as possible. I used photocopies of body outlines known as casualty monitoring report figures (DH Emergency Preparedness Division, 2010) in the format of A4 paper. This size was easy to bring to bedside for the patients to work with. I wanted to be able to work with people who could not come to the computers. Normally a casualty monitoring report is filled out for the victim by a witness or an observer of an accident. I offered pencils, erasers and sharpeners, watercolour pens of various nib sizes and coloured Sharpie pens. In this exercise the patient defines and illustrates what is happening in and on their body from their perspective.

I offered a male, female and gender-neutral outline as well as hands, head and brain outlines. The outlines were photocopied onto ordinary paper and were used as tracing templates. I made available drawing paper of a heavier weight for the outline to be traced upon in pencil. There were black Sharpie pens available to darken the pencil outline. The patients chose which outlines they wanted to work with. The process of tracing in pencil and then the pen is focused and meditative simultaneously. I then encouraged the patients to abstractly or figuratively draw in the outlines what they were feeling or thinking in their body at that moment.

It was made clear that they could talk as little or as much about their body map as they wanted. See the outlines below:



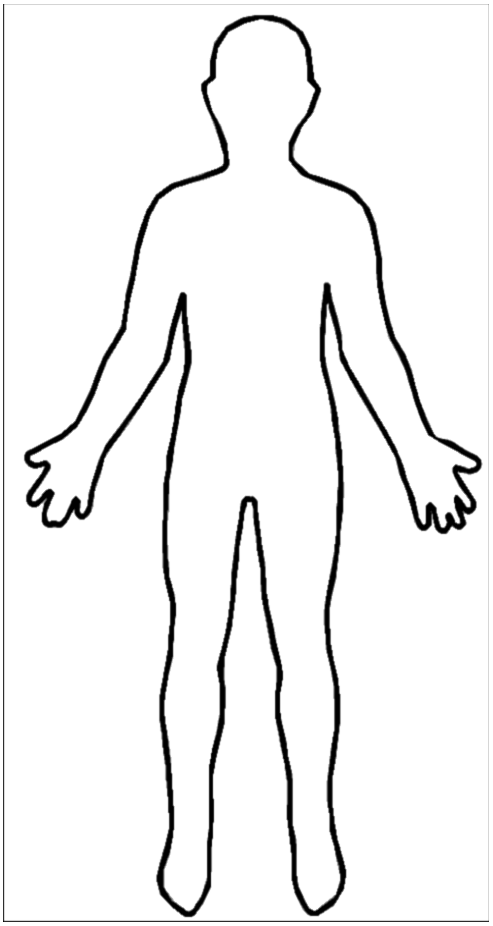


Fig. 18 Female outline

Fig. 19 Gender-neutral outline

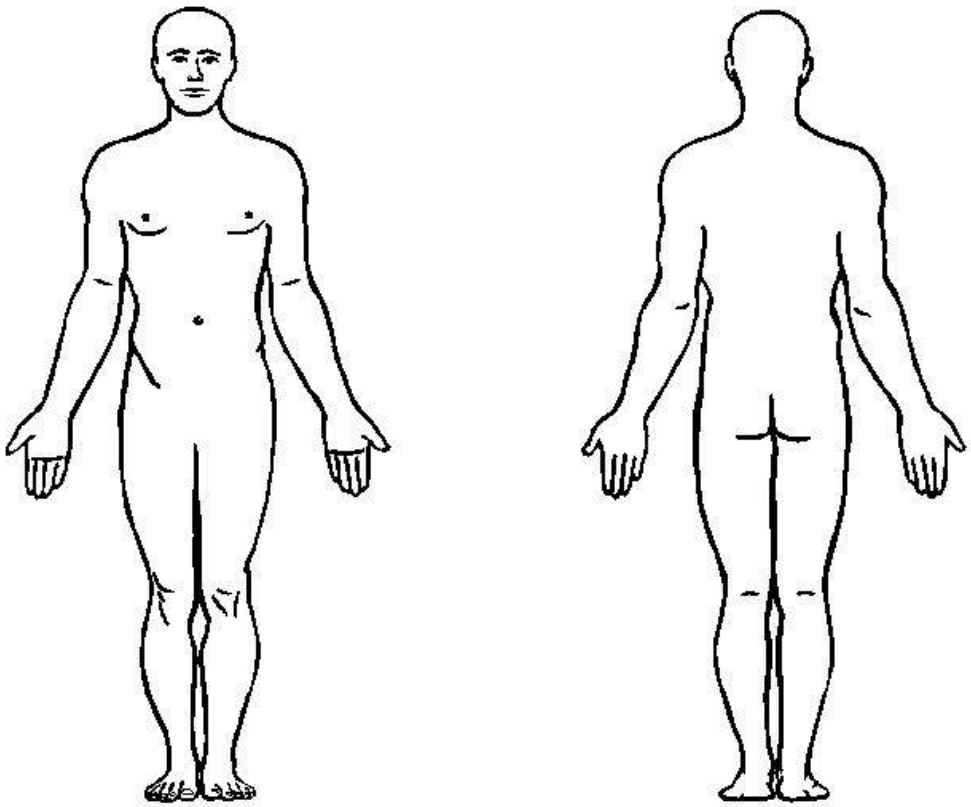


Fig. 20 Male outlines front and back

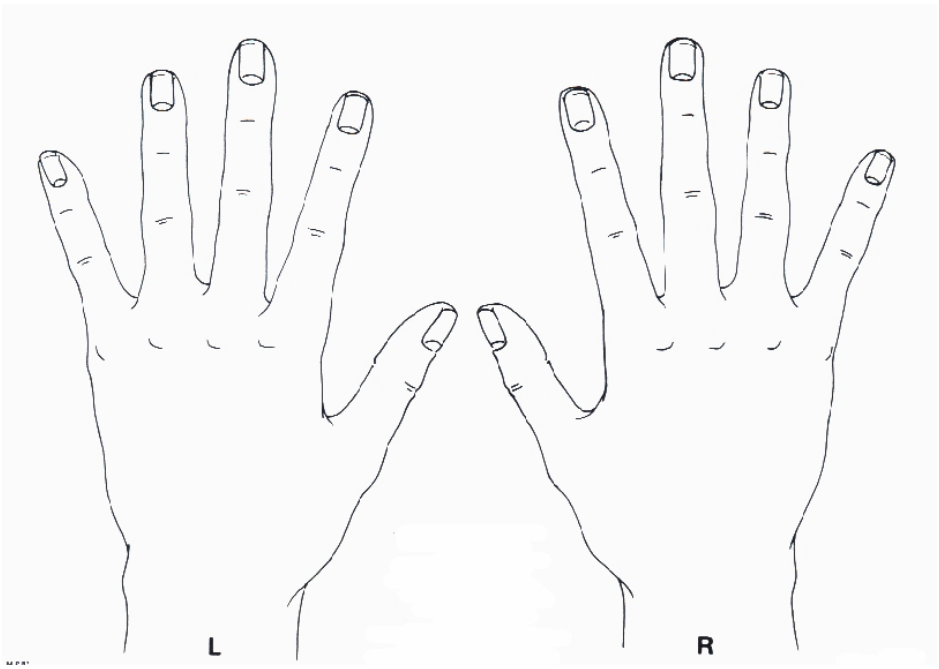


Fig. 21 Hand outlines

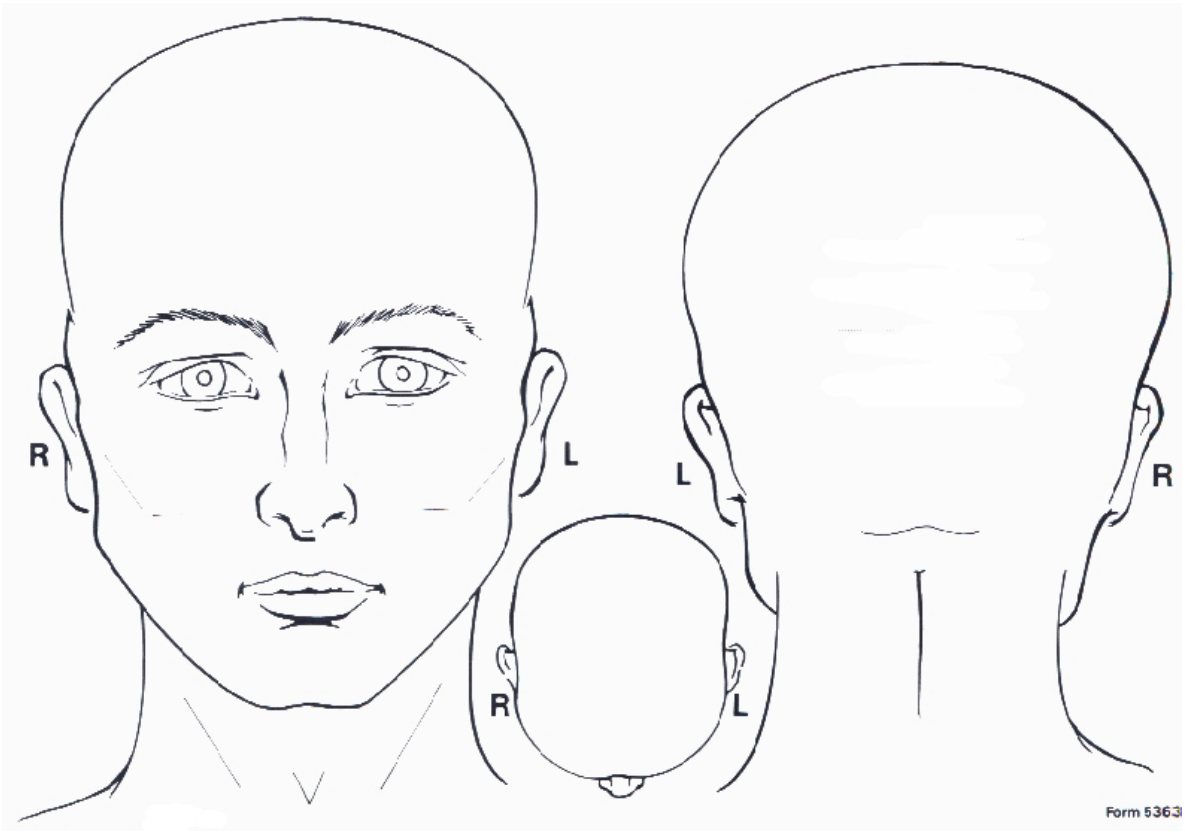


Fig. 22 Head outlines

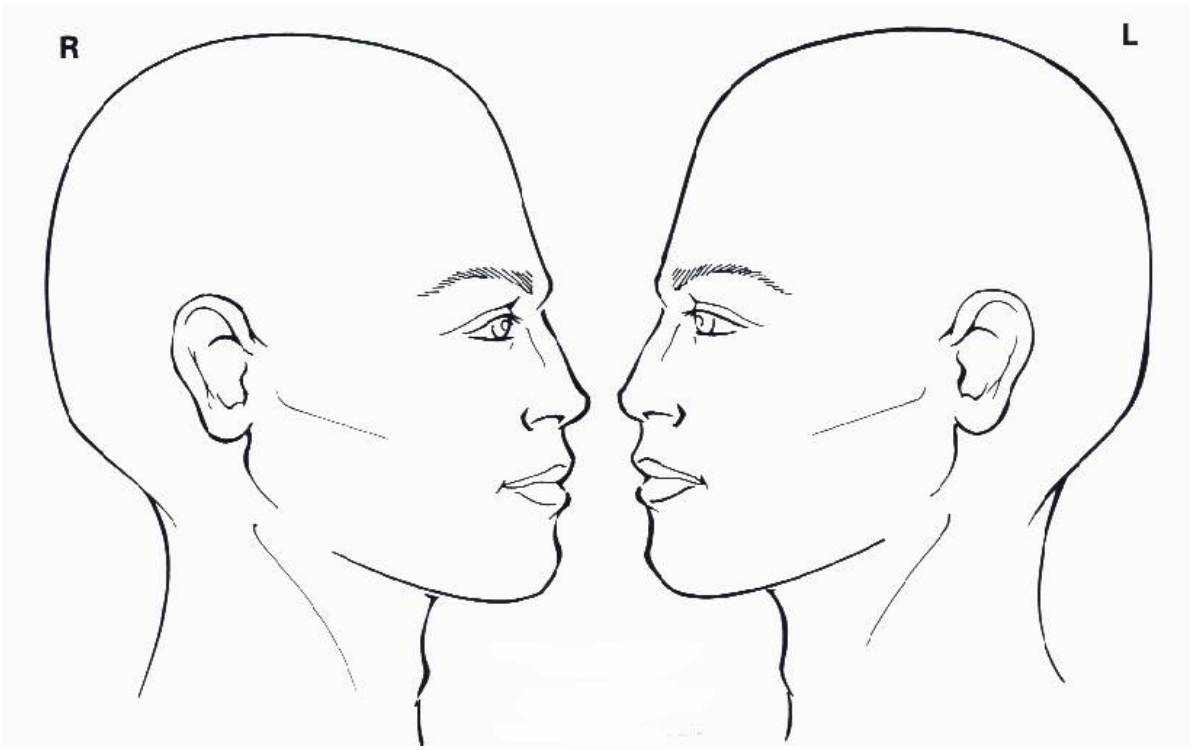


Fig. 23 Profile outlines

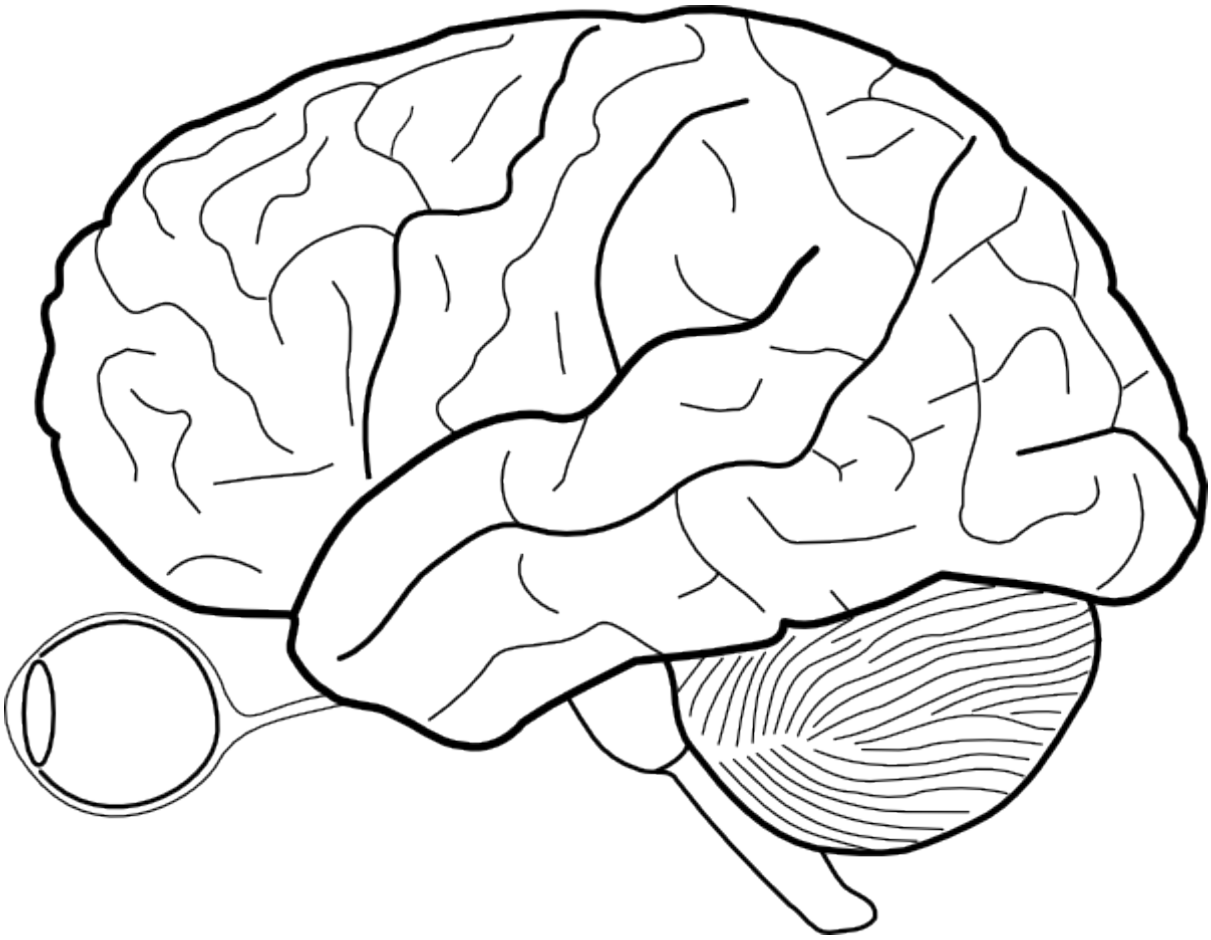


Fig. 24 Brain outline

I showed the participants body maps belonging to other patients that had been made in previous workshops to give them ideas of what was possible. I found that the patient would talk a lot about each item they were drawing. The act of drawing and talking together created a specific way of communicating between myself and the patients. The activity also created a way for the patients to connect with each other. In one workshop two patients were drawing together and found out that they both lived in the same neighbourhood.

Fig. 25 Patients drawing body maps (2015).

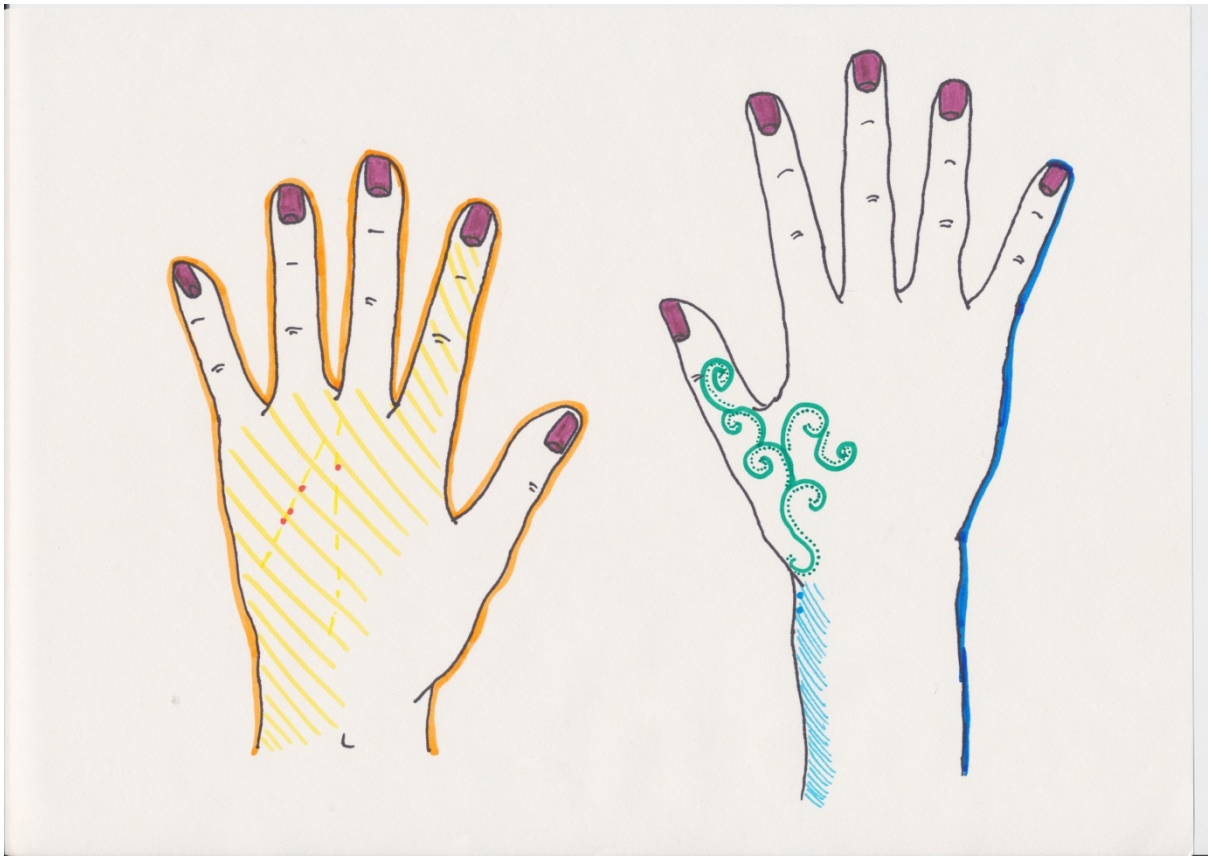


Fig. 26 Hands body map (2015).

Drawing body maps

In this section I include selected body maps to provide examples. A broader sample is included in the evaluation in Chapter 6. In the hands body map the patient drew red dots on the left hand to represent where the cannula, a tube that is inserted into the body for the delivery or removal of fluid or gathering data, was inserted to drip chemotherapy into her body. She said that the yellow lines represented the pain that radiated from the punctures. She drew the green swirls and the blue outlines as a way to counteract the pain, a way of self-soothing. This is evidenced in the following journal entry where she assigned specific meanings to the colours she chose.

April 23, 2015

I worked with a young woman, Participant K. She had had her cannula removed from her hand after having intravenous chemotherapy. She had four small red holes on her left hand. She chose the hands body map to express what was happening in her hands. She identified the colour yellow to signify pain and drew yellow lines diagonally on her hand extending to the tip of her forefinger. She said the pain continued to the tip of her finger. She drew an orange line along the outline of the same hand, the yellows and the orange giving off a warm or hot image. On the right hand she drew curly green lines that looked like plant growth or a decorative design with tiny dots. She drew small light blue hatches along the wrist and forearm. She drew a darker blue line along the wrist up to the pinkie finger. She said that the design she had made her on her right hand meant that she was beginning to feel better. The blue signified being calm and cool and the green meant growth.

I observed in this body mapping session that the participant began with addressing was is painful and then moved on to find a way to balance it with a positive image. The participant located some optimism by expressing pain through engagement with art.

Through body mapping the participants successfully communicated what was happening in their body at that time or at another time in the past as in the following body map. I was able to reach more participants with the traditional materials that were small and portable. This would be possible to connect with more participants with a tablet and a digital iteration of this exercise

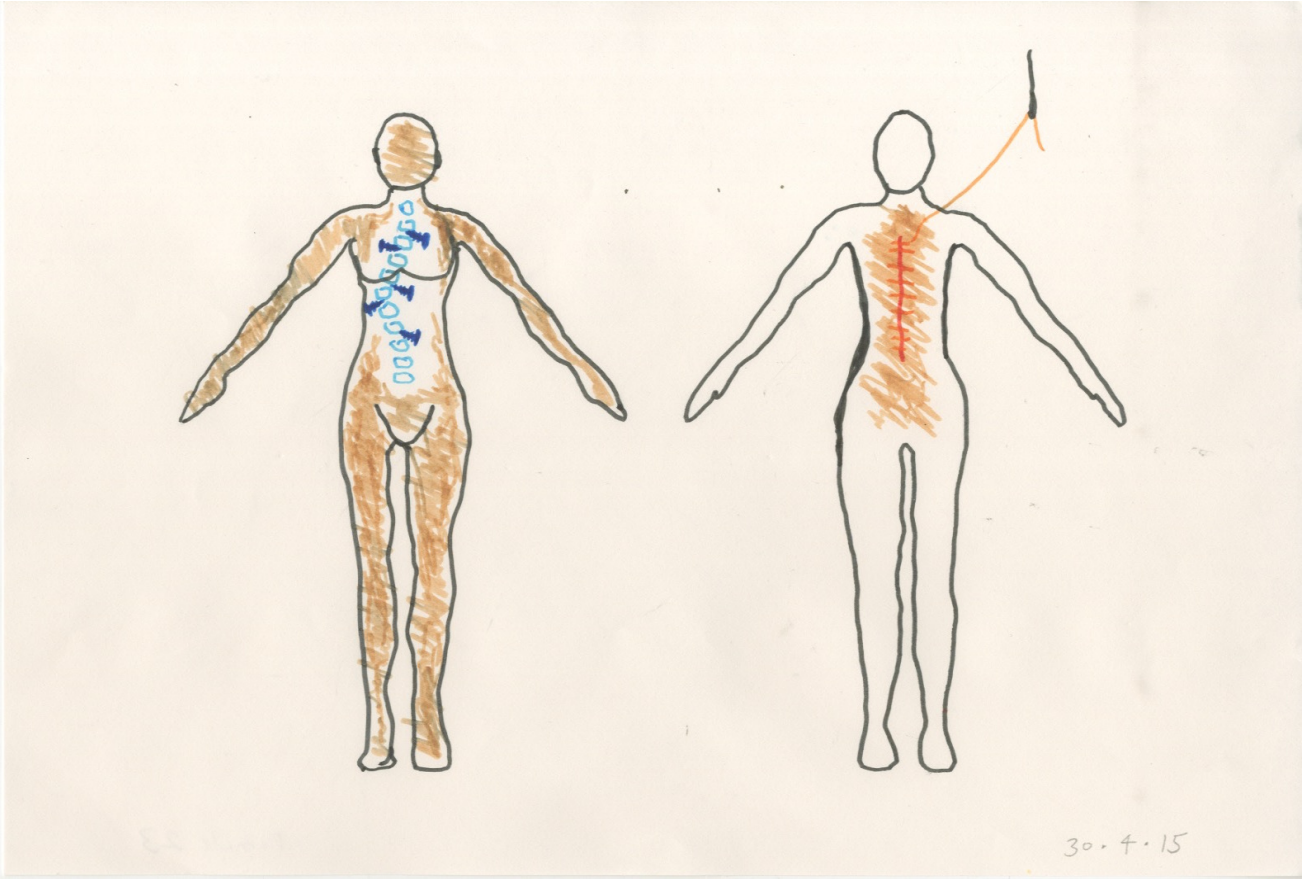


Fig. 27 Female body map (2015).

In this body map (Fig. 27) the female patient was able to visually tell her story of having back surgery because she has a crooked spine. She drew the screws that now hold her back in place. She said that she likes to sew; it is interesting that she illustrated the back being sewn up with a needle and thread.

April 30, 2015

Participant L is a young woman age 17 who was having chemotherapy in the clinic. I brought the body mapping materials to her at bedside. She chose the female front and back body map. She drew how she had surgery on her back when she was 12 because of having a crooked spine. She drew screws holding her still crooked spine in place. Then she sewed up the incision on the back with orange thread. She said that she likes to sew.

I asked her if her back felt better now and she said, “sort of.” I asked her if the back surgery was related to the cancer and she said no. She talked about her interest in crafts. I brought her a ceramic piggy bank to paint at the bedside.

In this body map Participant L revisits past surgery while having cancer treatment. This body map functions like an x-ray, making visible what cannot be seen on the surface of this young woman. I have encountered other patients within this clinic who have had multiple and consecutive medical procedures over the course of their lives. The body map outline provides a focus for the participant to dialogue with their body and express what they know and understand about their current physical condition.

The medical context that the participant is in and the casualty report outlines encourage the participant to take into account from their perspective their own corporal history. These accounts are not only valuable forms of self-expression, but they can also be used as tools for patients to communicate with medical professionals about the state of their body from their own perspective.

The body map format reverses the role of the medical professional and puts the patient/participant in the role of expert concerning their own body. This can be an empowering and strengthening exercise for the participant. The body map can also bring forward uncomfortable feelings and aspects of self that have been ignored or that the participant had no awareness of. Evidence from this study reflects views of the All-Party Parliamentary Group (APPG) who also think that:

> Creativity was also seen as a means of empowerment that can help us to face our problems or be distracted from them. Consistent with all this, it was acknowledged that the arts are not anodyne; they allow us to access a range of emotions, including anguish, crisis and pain, which can serve as a preferable alternative to being sedated (AAPG, 2017).

Being able to identify and recognise a range of emotions that are not always positive is a necessary part of accessing wellbeing. These emotions can help the patient get closer to understanding what may be contributing to their illness. This returns the power back to the patient to control what may be damaging their health.

Fig. 28 Gender-neutral body map (2015).

Five gender-neutral body maps were made in the workshops, including the one above (Fig. 28). The remaining four are included in Chapter 5. This one was made by a young man who was supporting a friend with cancer. He was insistent that he could not draw. He mentioned that he thought that his figure looked like a rag doll. He spent about 35 minutes with me and some other patients at the table talking and interacting.

Fig. 29 Head body map (2015).

None of the patients selected the male body map to draw on. I will discuss this in the analysis. The head body map (Fig. 29), as described by its creator, demonstrates six stages of chemotherapy as numbered geometric abstractions on the back of her hairless head. She said that she felt comfortable expressing this process in a non-figurative way. She made this body map at the bedside while receiving chemotherapy. The straightforward face looks as though it has a colourful skull cap on.

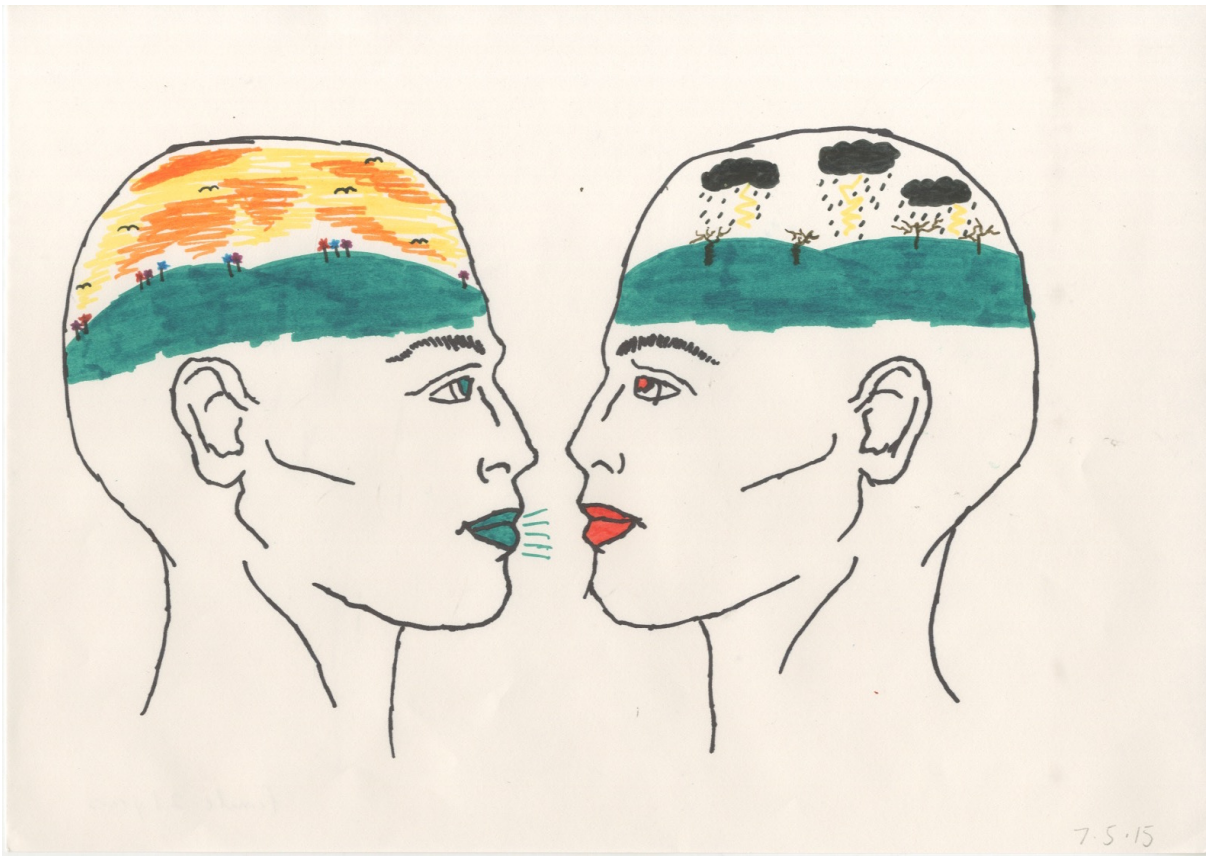


Fig. 30 Profile body map (2015).

In this twin profile body map the patient described the figure on the left as her good day (Fig. 30). This body map is an example of a figurative approach. When she is feeling well it is as though the sun is shining and she feels free to express herself through speech, signified by the green lips and green parallel lines drawn next to the lips. The right side represents a bad day; there are black storm clouds, rain and flashes of lightning. She coloured the lips red to signify the stopping of speech. The two profiles are animated by her drawings; they appear to be one person interacting and communicating with oneself.

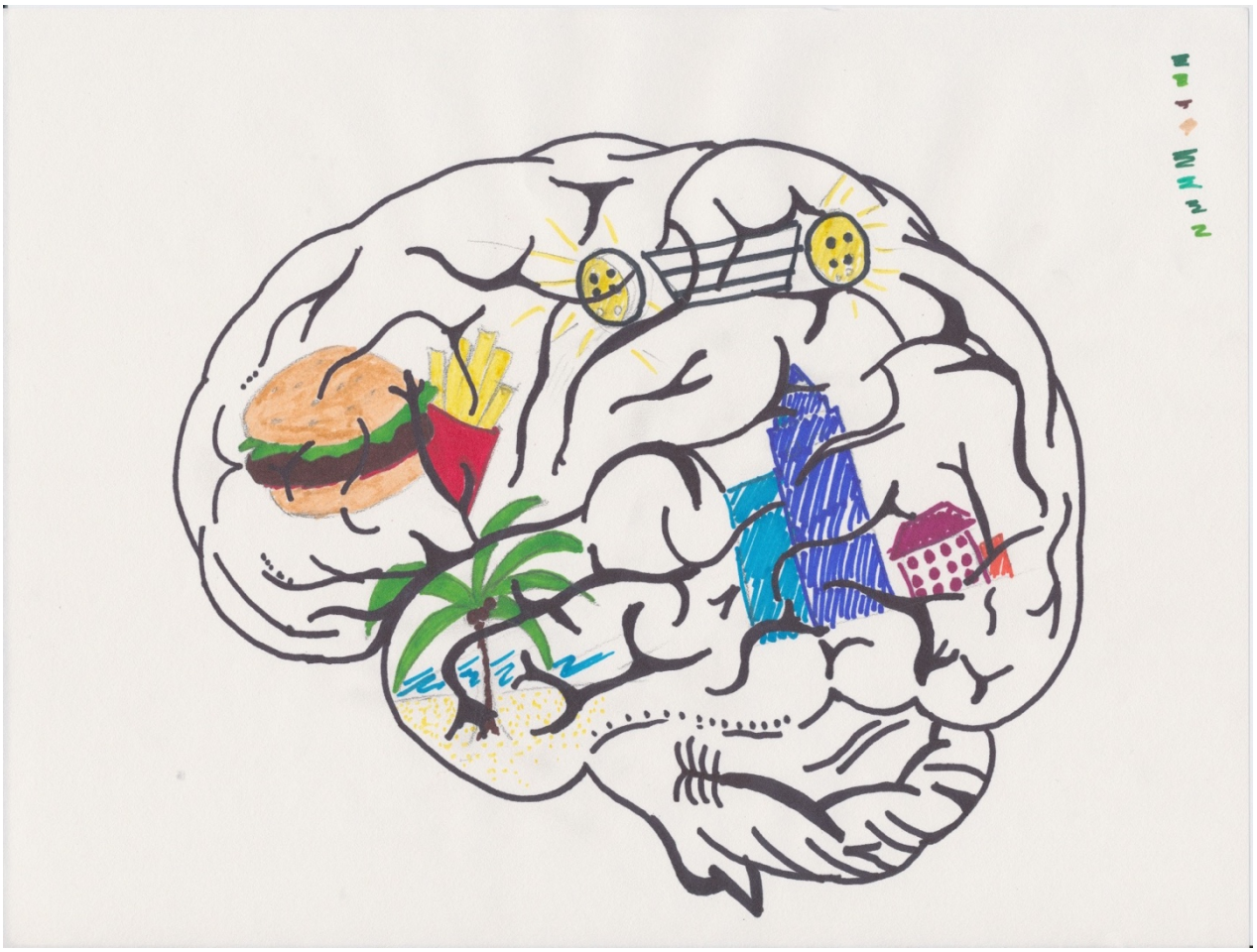


Fig. 31 Brain body map (2015).

The brain outlines were popular among the male patients. In this example (Fig. 31) the participant uses figurative techniques. The imagery of fast food literally on the brain within the context of cancer treatment could be viewed as a self-reflexive preventative measure awareness. He explained that he wanted to have a car and be in a city that offered sunshine and the beach.

Using the traditional art method, I observed that pens and paper have their limitations for enabling the participant to imaginatively tell their story visually. There are advantages to the immediacy that traditional art media has, such as the tactile experience of holding a tool and feeling the paper. Getting ink or graphite on your hands and using an eraser to edit mistakes creates a tactile embodied experience.

By focusing on the various body map outlines the participant was able to isolate a bodily sensation and give it form through abstract expression. The pens can communicate this clearly. I can also envision how this same exercise done in digital art applications could extend the expressiveness of the body map. The capabilities and features can even add to their story and amplify the expression of the participant. The visual data began to reveal that

there could be a marriage between methods in the design of a digital art therapeutic protoype.

After facilitating over 42 body maps with individual participants (which are included in Chapter 6, the evaluation), I concluded that body mapping is a successful method for collecting data with the TYAs. This leads me to the next exercise, which is a combination of both the AAPC and the body mapping method that I present in the following section.

Body map collage

I arrived at the decision to experiment with making a full-sized body map out of collage elements. I chose to work with print images cut out from current magazines and newspapers. By invoking the contemporary DJ as a cultural figure who is a new kind of author and biographer, I offered an alternative voice for the patients to experiment with and a figure that the TYAs could relate to. The DJ produces music by mixing existing tracks in real time using multiple electronic hardware devices. The DJ exhibits a new kind of logic through selecting and combining pre-existing elements to create new artistic forms.

By working with both digital art and traditional art media the boundaries between the research activities began to blur. Throughout the workshops I asked the patients questions about the body mapping visual autobiographical story telling method to find out if they thought that it would be useful to translate the activity to a digital medium. I asked the patients during the digital workshops how they felt about expressing themselves through digital art. These questions and their answers informed my prototypes. Below are a body map collage and journal entry.

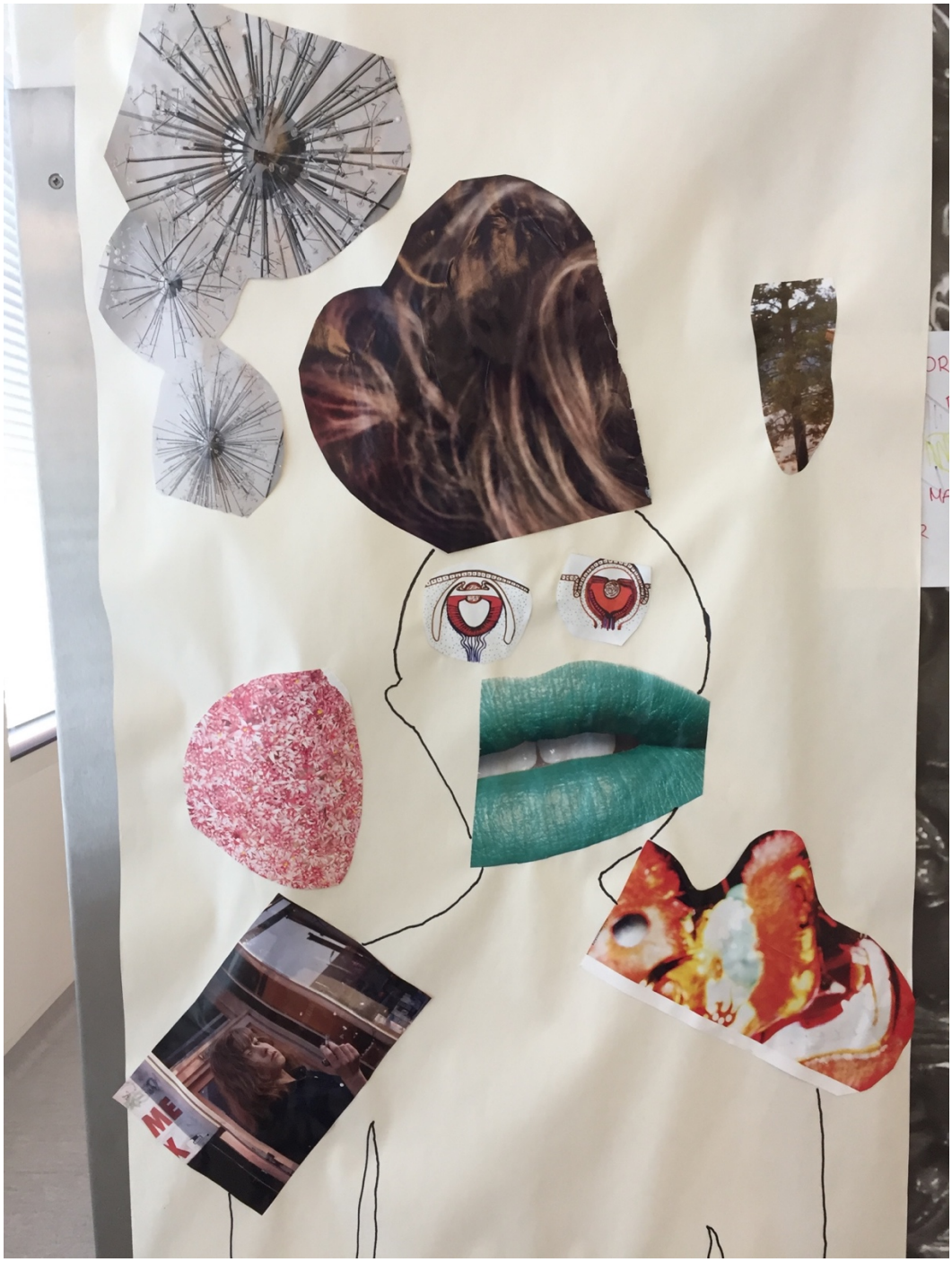


Fig. 32 Body map collage 1 (detail) (2017).

Fig. 33 Body map collage 1 (2017).

March 9, 2017

Today was the first day that I experimented with the collage on the body map with the TYA participants. I got out a long piece of butcher paper and pencilled in a simple outline of the body. I cut out dozens of random images from fashion, psychology, art and home-decorating magazines. I made them available in a pile. I connected with a young woman, Participant M, who is about 20 years old. She was having a bone marrow sample. She has had cancer treatment previously, and again now has a tumour. She emigrated from Romania when she was three. She likes makeup – cosmetics – and likes to watch YouTube demonstration videos about how to apply them. She said that she has only read one book in her life; she describes herself as a visual person. The one book that she has read was an anatomy book. She said

she does not like stories, novels or fiction. She would rather watch them. I had cut out an image of a young woman smoking. She was drawn to this image and attached it to the shoulder on the body map. She went on to tell me that her friend suggested that she smoke cannabis to help with her cancer symptoms. She said that she has tried it a few times.

The collage body map is effective for generating personal narratives. Like the DJ, the participant is able to mix disparate images as well as draw images that form a non-linear autobiography. The author can tell as little or as much as they wish about their body map. The body map is interactive in that the images can be interpreted by the viewer bringing to them their own perspective as well as creating entry points for discussion about the significance of the chosen imagery.

The body map collage is an iteration of the AAPC. However, the AAPC is a disembodied experience of creating personal identity through an assemblage of ready-made images in a virtual space, whereas the collage body map aims to re-organise exterior experiences and feelings within a representation of the human body, a re-embodiment of identity constructed from selected cut-out print media images. The two exercises are related in their use in that one works with the mind and the other with the body. On the following page is a body map created on May 18, 2017.

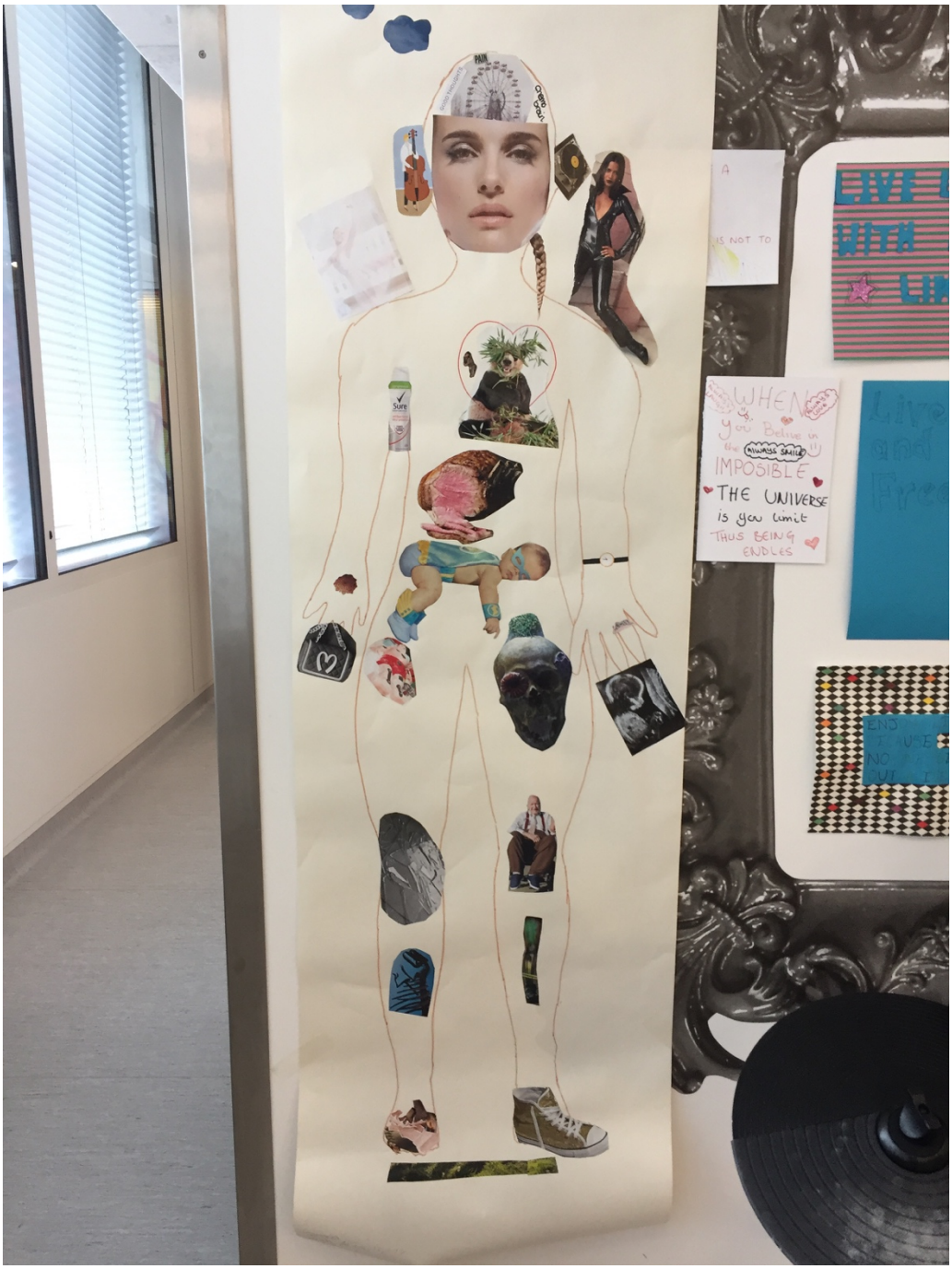


Fig. 34 Body map collage 2 (2017).

May 18, 2017

Today I worked with a young woman, 20 years old, on a collage body map. She was talkative and open. She placed the iconic National Geographic picture of the young woman from India in a black collared PVC jumpsuit (Parameswaran, 2002) on her left shoulder and a ballerina on her right shoulder. She said that they were like her devil and her angel on her shoulders. She felt drawn to the panda bear eating shoots and leaves in her heart area and drew a heart around it. She said she thought the animal was cute.

She cut out a deodorant bottle and put it in her armpit area. The chosen imagery varies from practical illustrations, archetypical and emotional. Natalie Portman's airbrushed face, looking much like a mask, is placed on the head. There is a Ferris wheel on top of the head, which, she says, looks like how her head feels spinning round and round. The words 'good thoughts', 'pain' and 'chemo brain' were placed around the wheel.

She likes to listen to music, so she cut out a record player with a record on it to place next to her left ear and the devil character, and a violin next to her right ear beside the ballerina.

Childlike cut-out clouds rise above her head. She spent a lot of time cutting out tiny feet to fill in the right foot and cut out a large Converse shoe to put on the left. She cut out a tiny watch for her wrist and a handbag. She complained that her knees felt like she is an old person and cut out an image of an old man sitting down and pasted it on her left knee. On the right knee she placed a large image of shattered glass and a t-rex skeleton. She included an image of the classic Hasbro game Operation.

The image that she spoke the most about was the baby sleeping in a superhero mask and cape that she placed in the abdomen area. She said she was afraid that she would never be able to have children because of her cancer treatment. She also said that she spends a lot of time with her cousin's baby and that she wants to steal the baby. She said she was just kidding then she said she was serious again. She included a scan of a foetus near her left hand that has the word 'love' cut out like a wedding ring on her ring finger. There is a large piece of meat being sliced above the baby.

This participant related easily to the print images and was able to use them to talk about herself. The activity of cutting things out and glueing them to the paper created a rhythm to the conversation. Her focus was distracted as she engaged in the activity. There appeared to be a logic to how all of these images related to one another on the body map. She was able to address concerns and develop questions about her health that were important to her. She was also able to articulate that her head feels as if it is spinning when having chemotherapy. This participant is able to pinpoint and describe physical sensations and questions about the future of bodily functions within the context of her cancer treatment.

Working with one participant I can assist them to generate a complex narrative. I found this out while I helped the participant above cut out tiny feet to put inside the right foot. The process was interactive since I could provide an extra hand in helping to cut out

images and to listen to the participant's story. I found that after she cut something out and talked about it, then glued it down, the next part of her story would unfold. The use of printed images and a collage technique produced a descriptive dialogue with the participants. The body map outline provided the place for narratives about specific locations in the body to be generated. The images were effective tools for assisting the participant to describe their physical state. I decided to bring forward the use of cut-out printed matter and the collage method of filling in the body map to the next iteration of this study.

Collective body map

After working extensively with individual participants, I realised that the next step in this study was to facilitate a collective body map process amongst the TYAs. I was interested in how the body mapping method could be used to collect data from the TYAs as a group. I observed the participants interacting with each other when working on their own body maps and how that produced conversation, though without any outward signs of working together. I wanted to observe the TYAs interacting while collaborating on a shared theme and outcome.

I speculated that if they were to work on the same body map that the participants would work together to express a shared experience of cancer treatment. For this exercise I drew a life-size gender-neutral body outline on a roll of paper. I placed it on a table that could seat more than eight people around it. I set out scissors and glue for pasting down images. I got permission to use the outdated magazines that were around the Hub to select images from. I also used the magazines that I had brought. I was able to recruit six participants: four females and two males. They sat around the table talking about the images and which ones that they would cut out and paste onto the body map.

I found that the TYAs thrived on interactivity. This is evidenced in the collective body map (see Fig. 35), made on 10 June 2017. The body map is full of similar types of imagery of young people using their voices to sing. This activity opened up a forum for discussion, decision-making and camaraderie. The aesthetics and choices in the imagery began to express aspects of the TYAs' reference points. A journal entry from the same day reveals the group dynamic and some of their cultural references.

In the collective body map experience the wellbeing indicators of inclusion, respect, feeling safe and being active together were evidenced through the imagery and

conversation generated by the participants. For example, the inclusion of LGBTQ imagery included in a central place on the map indicates that the participants felt safe to express themselves. There was respect amongst the participants in accepting diverse artists from different genres to be represented collectively on the body map. The participants chose to be active and social and work towards a shared outcome.

Fig. 35 Group body map (2017).

8 June 2017

The Manchester Arena bombing at the Ariana Grande concert was still fresh in the TYAs' consciousness. Together they cut out many images of her and other singers. I do not know who the blonde singer is. There are some men singers; one of them is Chris Martin from Coldplay. The images of the women artists are bigger and more prominent. The male participants were cutting out the male artists and the female participants were cutting out images of female artists. There is a man with a shovel, the face of a clock, a baboon and some birds. In the chest and heart area there are some graphic novel characters that represent the LGBTQ community. There is an image of a girl holding a portrait of a young girl. On the right shoulder are a blue angel and a skull. There are two images of children with electrical nodes attached to their heads in a skullcap style. Singing and voice, in particular a feminine voice, seem to be featured. The group body map facilitated a social space with up to six participants, male and female, ages 14-24. The body map was made around a table while participants cut images and shared their thoughts.

I understood the participants' desire and need to be heard. As a group they created a powerful voice. The number of individuals telling their story makes the impact of the body map powerful. When the participants work as a group, they are able to choose topics to focus on. The format of the collective body map creates a space for the participants to listen to each other and discuss and archive their combined experience of cancer. This shared space can create a sense of inclusion and have therapeutic effects. Through collaborating and being active, a shared voice emerged. Amongst themselves they produced an optimism that was evidenced in the singing performers.

They were able to find a collective voice and represent themselves as a diverse group of individuals as evidenced by the LGBTQ community imagery in Fig. 35. As a group, the participants energised each other and showed respect for each other throughout the process. The images of the children with the electrical nodes alluded to their awareness of the technologically mediated medical procedures that they are experiencing.

When there are many voices speaking out about the same individual experience, it has a bigger impact on an audience than one single voice. When the body map was complete, they wanted me to display it on the wall beside the positive affirmations that patients had made at another date.

For future iterations of this exercise I see it being used as an exploratory probe to collect data about a specific shared experience; for example, the experience of having cancer

treatment in the same bodily location, such as the brain. Alternatively, participants can be asked to concentrate on visual imagery that they associate with having a bone marrow transplant and create a body map with their imagery.

The collective body map has scope for creating new data for medical professionals while at the same time giving agency and voice to patients about their own experience of their medical conditions. Participation in the collective body map evidenced the promotion of health and wellbeing through being active, feeling included, achieving, and being nurtured by their peers. In terms of the personal dimension the participants displayed reduced anxiety and increased optimism. In the social dimension there was a sense of belonging, expression of identity, sociability, new connections and bonding amongst each other.

Chapter 5: digital prototype sketch tools

The observations, visual data and experience that I gathered during my data collection period built the foundation for this digital prototype sketch. It is only one visualisation of how this application can be actualised. I see this sketch as research to be added on to, expanded and developed further with the swiftly changing technological landscape.

I used Adobe Flash CS4 Professional (which is now 10 years old), as my sketchbook to give detail to the findings of this research. Over the time of my research project, the web has evolved and open standards including HTML5, WebGL and WebAssembly have matured over the past few years. Given this progress, and in collaboration with several technology partners – including Apple, Facebook, Google, Microsoft and Mozilla – Adobe is planning an end-of-life for Flash. Specifically, Adobe will stop updating and distributing the Flash Player at the end of 2020 and encourage content creators to migrate any existing Flash content to these new open formats (Adobe Corporate Communications, 2017).

The new incarnation of Adobe Flash is called Adobe Animate CC and was launched in February 2016 (TechCrunch, 2016). I support the approach that award-winning designer Dr Wendy Keay-Bright takes in using up-cycling. She believes that there are older technologies that are overlooked and have not yet reached their potential, having undiscovered magic still in them. This is a result of society's constant search for and preoccupation with the next new technology (Network Autism, 2016).

Up-cycling can be beneficial to web ecology. Brian Barrett, the news editor of *Wired* magazine, suggests that 'the web is already littered with the artefacts of outdated standards, though; it's an unfortunate but predictable side effect of barreling into the future' (Barrett, 2015). For this prototype I prefer the aesthetic of Adobe Flash CS4 Professional. I want the prototype to have a cut and paste upcycled-retro aesthetic to it.

Female digital art tools body map prototype

For this prototype I played the part of the participant. I found the exercise challenging and very different from working with traditional media. When working in Flash it is a collaboration with the application. The software application becomes a medium itself with its own historical background and character. It is a collaboration with all of the developers who have researched, designed and engineered the medium. This changes the context of the art artefact, placing it within a media legacy that only began with the advent of the personal computer. Below are screenshots of the digital body map sketches along with my journal entries.

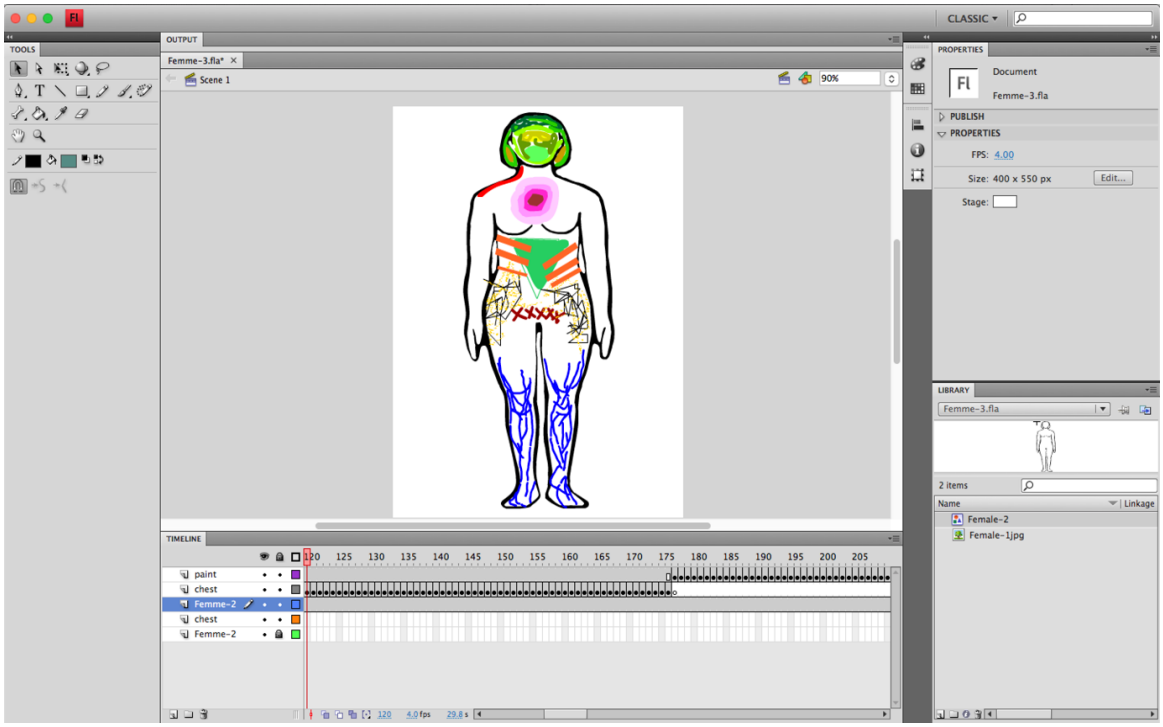


Fig. 36 Flash CS4 Professional screenshot – body map REM 1.

Fig. 37 Digital body map REM 2.

Body map journal

September 24, 2018 REM

As I am drawing digitally within my body map outline, I feel congested in the top of my head and in my face. I am choosing blue and green colours that remind me of phlegm. I stopped at the head and will continue tomorrow.

September 25, 2018 REM

I had trouble finding my timeline that I created yesterday. This is one of the main differences between using technology rather than analogue methods for body mapping. It's great for the editing capabilities, though if something gets lost it can be distressing. Luckily, I recovered it before I started a new one.

I have begun today by placing orange bars in the rib cage area. When I was pregnant with both of my boys, I could feel them pushing on my ribs. It was a very strange feeling. I notice now that my right rib cage is higher up as though it was pushed out of place. My rib cages are not symmetrical now. The green triangle sits with the top facing down in the cave of my ribs. This part of my body feels as though it has changed since giving birth as well. The green represents my longing to breathe air that is not polluted. I walk everywhere, so I am exposed to car emissions whenever I travel by foot.

I drew a rusty coloured circle in the chest area with dark medium and light pink halos around it. My heart feels like it beats very fast when I drink too much caffeine. My family has a history of atrial fibrillation. This concerns me. I am now reminded to carefully monitor my impressions of my heart.

The small x's above my pubic area are the scars from the two caesareans I had during childbirth. The scribbles in black and yellow in the hip area and also the lower back area indicate a pain that I get in my back and hips. Sometimes it feels as though a shock goes through my lower back. I have had lower back problems since I was 13.

The blue veins starting in my feet and up into my calves indicate use and muscle, also my calves and hamstrings tightening from pushing a buggy and walking as transportation.

September 26, 2018 REM

I had lost the timeline, but I recovered it though it has morphed into something else. The final product that I include in this thesis turned into an experience of making art in the fine art sense that I was trained in. I had to work with the mistakes and surrender to a computer-led improvisational process. The computer and the flash software took over and began playing with my images, disrupting the control that I had over my prototype. It was frustrating but then suddenly I was reminded of what it is like to make a kind of computer art that I love. I have decided to restage the lost body map prototypes from September 24 and 25, 2018.

Creation 2

While recreating my body map, I tried to stay as true to the original as possible. I continued where I left off. I have added red and orange paint starting at my neck and continuing down to my shoulders. My neck is easily strained and sometimes my shoulders become sore from carrying too much weight. I painted a dark purple stroke down my arms to my hands reminding me how my hands freeze up sometimes when I over-use the computer and also when I paint for long hours with a fine brush. This affects my arms at the same time. I have to remind myself not to over-use my hands and arms.

Advantages and disadvantages of using digital art media for making a prototype

The drawing and painting tools in Adobe Flash CS4 are not very refined in comparison to more updated versions. They are basic and can be compared to basic colouring pens, pencils and paint brushes. I am using them in a similar way to traditional tools by not adding any filters or effects.

When drawing on the computer I find that I edit much more than I would if I were drawing, painting or sketching on paper or any other surface. The editing capabilities are the main advantages for image manipulation in digital art applications for the arts in health activities that I facilitate. In addition, the abilities that digital media have to express the contemporary subjectivities of the participant is an important feature. The reproduction capabilities of the files that are produced are an advantage for creative media interventions.

It is a concern that technology is not available to everyone, and not everyone has the time or funds to learn how to use it. Having access to computers, smartphones or tablets is a

privilege. There is a growing concern that populations that are not digitally literate or cannot access technology will be excluded from the digital care that is now being made available.

Body map collage digital sketch

In this sketch I integrated aspects of the body map collage by using found images from the internet to work with. I did this by altering them and transforming them into symbols to be stored in an archive. The images can then be manipulated in Adobe Flash CS4. Using the digital prostheses of the computer to search for images adds to the research process. One can easily access definitions and research the meanings behind the images to find context for them. This is a very different experience from cutting out images from magazines and printed matter.

As the artist who is designing the symbol archive, I aimed to create a cohesive aesthetic style by first removing the backgrounds from the images. Then I reproduced two copies of each one, the first a low-resolution replica and the second a trace bit map effect that gives the image a loose painterly style. The result is a choice between a photo replica and a graphic novel-like image. Below is a screenshot of this symbol archive followed by a collage body map sketch (Fig. 38).

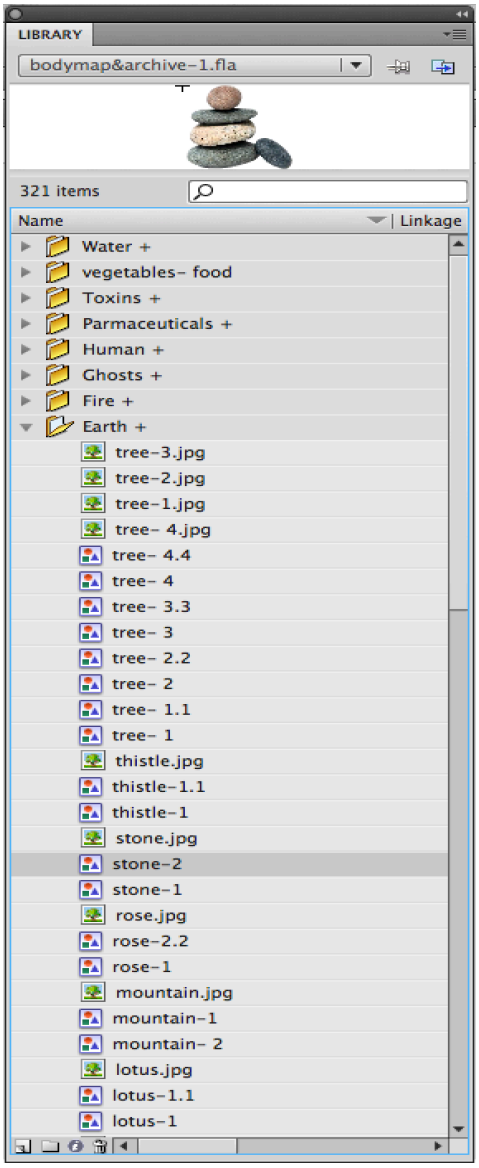


Fig. 38 Body map collage image archive - 1

Fig. 39 Digital body map collage REM 3

Body map key with journal

September 20, 2018

Using the archive images to assist with the journaling I added text beside the symbols to create a descriptive key to the map. I found that the symbols supported the journaling acting as an anchor for describing my body's experience.

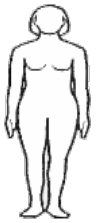


Fig. 40 Female 1.

I am starting with the generic female form. Instinctively I am drawn to this form because it is not specifically referencing a specific body type. It is not very large nor very slim. The breasts are neither very large nor very small. The drawing is based on the body outlines that are used in medical incident reports. I have traced the outline with black paint to give it a hand-drawn effect.

Fig. 41 Spark 1.1.

I have a cavernoma on my brain on the left occipital lobe that is the source of epileptic fits. The spark image looks as though it has come out of nowhere. I make this visible on my body map. It is part of my life that I do not usually share with people.

Fig. 2 Alien 1.

I placed the alien in my throat area because that is where my voice originates. I identify with the alien because I am from the USA. My accent distinguishes me from British people even though I speak English. I feel as though culturally I am from another planet. There are positive and negative aspects of being alien.

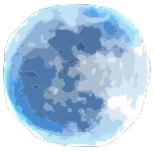


Fig. 43 Moon 1.

The moon is far away, and it is constant but mysterious at the same time. It has craters. It is silent but is powerful in its silence. I frequently keep quiet about what is bothering me or is painful for me. I put the moon on the lower half of my face where my mouth is. I feel this is connected to my feelings of being an alien.

Fig. 44 Pills 1.1.

The pills stand in for the lamotrigine that I take as an anti-epileptic medicine. I do not like taking this medication. Lamotrigine can be effective for bi-polar disorder as well. I feel uncomfortable with the associations with such a mental disorder even though I take it for epilepsy. I feel as if people know what kind of medication I use I will be judged.

Fig. 45 Cave 1.

The cave is placed in my stomach area and the ribcage area. During both of my pregnancies, the unborn child was constantly pushing on my ribcage. After they were born there was a different kind of bulge that was not there before I had children. The cave reminds me of what is hidden in that area. It stores food, organs, children. It also reminds me of a place to store emotions, a place to hide things like treasure. The heart is also in that area.

Fig. 46 Lotus.

The pink lotus is growing out of the cave. It brings me hope that there are ways to heal my body. It leads me to find out how to care for myself and my body. It represents self-care and a reminder to listen to my body for clues on how to do so.

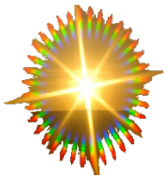


Fig. 47 Solstice.

My arms are very important to me. I need to have the strength to pick up my children and to perform daily tasks. They are a fundamental part of using my hands, which I use more than anything. Arms are very expressive and valuable. I put the solstice image to honour my arms and keep them strong.

Fig. 48 Ghost 4.4.

This image reminds me of the Goths in the 1990s. They wore white face makeup, dark eye shadow and mostly black clothing. The music of Siouxsie and the Banshees and Joy Division were influential. I admire the theatricality and expressiveness of the Goth culture. I recognize the risk in expressing the dark or shadow side of oneself.

Fig. 49 Lightning.

I feel spasms of pain that originate from the lower area of my left side and back. This is very painful for me. I have had lower back pain since I was an adolescent. I started going to a chiropractor when I was 13.

As I sketched this prototype, I noticed that I was taking a self-diagnostic approach to my body map. My inclination was first to explore the difficulties and problem areas. This conflicted with an urge to acknowledge my strengths and to counter the difficult areas with areas that I chose to represent my strengths, using positive imagery to represent these characteristics. Below I have created a complete key of all of the symbols in the archive.

Prototype sketch symbol archive key

This symbol archive key provides words that relate to the symbols within the archive of this prototype. Each image is assigned five words that can be associated with the symbol. This format is intended to represent the hyperattentive mode of consuming and digesting media, which was set out by Katherine Hayles (2008). The hyperattentive mode is the counterpart that works with the brief body map experience that is built into the design of this prototype. I elaborate on this in the final section of this chapter.

This archive is provided only as a point of departure for the user. It is not to be used as an emotion prediction tool, or to define the user's affective experience for them such as in the International Affective Picture System (Center for the Study of Emotion and Attention, 2018). These symbols are provided as a selection of visual narrative building blocks. The images can be used in any configuration of figurative or abstract representation. It is up to the user what meaning is attached to the images – or no meaning – and can be used for their unique formal attributes. The images are meant to be used in relation to one another. Two or more images can build a visual narrative that communicates the user's state more clearly.

The images are grouped into the categories of earth, water, fire, air and cosmos and are based on the five elements found in nature. Within these groups are subcategories that particularise aspects of each group. The cut and paste style that I have adopted for this prototype is intended to remind the user of the analogue experience of making a collage with printed materials.

Earth

Fig. 50 Lotus.

Enlightenment, simplicity, beauty, sedentary, water.

Fig. 51 Rose.

Tradition, romance, perfection, rigidity, security.

Fig. 52 Thistle.

Wild, unrefined, sharp, protective, survivor.

Fig. 53 Cave.

Hermitage, safety, secrecy, loneliness, archaeology.

Fig. 54 Desert.

Dry, thirst, spaciousness, heat, wind, escape.

Fig. 55 Mountain.

Ascend, surmount, monument, slide, edge.

Fig. 56 Jungle.

Moisture, wild, tangled, overgrown, dense.

Fig. 57 Tree 1.

Tall, pointy, fresh, lush, protective.

Fig. 58 Tree 2.

Shady, leafy, roots, sap, climb.

Fig. 59 Tree 3.

Fall, branches, naked, hibernation, nest.

Fig. 60 Tree 4.

Spring, bloom, birdsong, allergy, fruitful.

Fig. 61 Stones.

Rocks, weight, grey, beige, tombstones.

Human outlines

Fig. 62 Female.

Person, woman, girl, her, a gender.

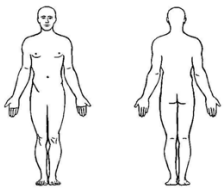


Fig. 63 Male.

Person, man, boy, him, a gender.

Fig. 64 Neutral.

They, them, human, person, themselves.

Human

Fig. 65 Eye 1.

Sight, soul, blindness, window, enlightenment.

Fig. 66 Eye 2.

Open, future, vision, cry, globular.

Fig. 67 Baby 1.

Birth, life, possibility, immaturity, growth.

Fig. 68 Baby 2.

Affection, childish, small, young, infant.

Fig. 69 Baby 3.

Immature, familiarity, responsibility, family, precious.

Fig. 70 Heart.

Love, blood, chest, oxygen, pumps.

Fig. 71 Lungs.

Breath, air, carbon dioxide, muscle, atmosphere.

Fig. 72 Brain.

Thought, electricity, neuroscience, mental health, mind.

Ghosts

Fig. 73 Ghost 1.

Otherworldly, spiritualised, past, unresolved, transparent.

Fig. 74 Ghost 2.

Sad, lost, alone, release, trapped.

Fig. 75 Ghost 3.

History, legacy, inheritance, honour, deteriorate.

Meat

Fig. 76 Meat.

Red, blood, protein, slaughter, guilt.

Fig. 77 Chicken.

Feathers, nutritious, murder, popular, acceptable.

Fig. 78 Fish.

Healthy, fresh, flaky, raw, swimming.

Vegetables

Fig. 79 Carrot.

Vision, root, pointy, crunchy, soil.

Fig. 80 Broccoli.

Stem, trunk, bulbous, fibre, tree.

Fig. 81 Asparagus.

Spear, triangle, long, seasonal, growing.

Fig. 82 Mushroom.

Magic, cup, mould, velvety, beige.

Fruits

Fig. 83 Strawberry.

Red, seedy, sweet, soft, innocent.

Fig. 84 Grapes.

Round, merry, wine, jam, abundant.

Fig. 85 Pear.

Texture, yellow, green, grainy, shapely

Toxins

Fig. 86 Toxins 1.

Smokey, coughing, grey, warning, image.

Fig. 87 Toxin 2.

Bubbly, light, sour, sweet, celebration.

Fig. 88 Toxin 3.

Amber, social, companion, wheat, consolation.

Fig. 89 Toxin 4.

Hard, depression, blackout, high, talkative.

Fig. 90 Toxin 5.

Sterile, anti-bacterial, burning, scent.

Fig. 91 Toxin 6.

Sugar, saccharine, artificial, compulsive, sprinkles.

Fig. 92 Toxin 7.

Fried, greasy, heart attack, obesity, ubiquitous.

Fig. 93 Toxin 8.

Confectionary, crystalized, bright, happy, tempting.

Fig. 94 Toxin 9.

Substance, rising, harmful, planet, politics, global warming.

Fig. 95 Toxin 10.

Microorganisms, ecology, cultures, reproduce, disease.

Pharmaceuticals

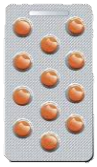


Fig. 96 Pills 1.

Medicate, cure, alleviate, overdose, manage.

Fig. 97 Pills 2.

Drugs, medicinal, manufacture, epidemic, pharmakon.

Fig. 98 Pills 3.

Opioid, addictive, biochemistry, sleepy.

Fig. 99 Hypodermic needle.

Inject, syringe, substance, abuse, heroin, sharp.

Water

Fig. 100 Waterfall.

Cascade, steep, ledge, descend, meditative.

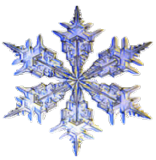


Fig. 101 Snowflake.

Frozen, uniqueness, emotions, fragility, white.

Fig. 102 Bubble.

Film, hollow, illusion, ephemeral, translucent.

Fig. 103 Bubbles.

Light, floating, burst, isolated, gas.

Fig. 104 Rainbow.

Reflection, refraction, dispersion, arc, multicolour.

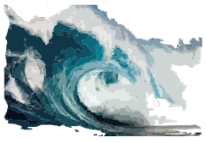


Fig. 105 Wave.

Energy, oscillations, water, crashing, tumbling.

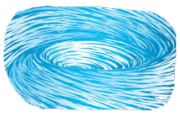


Fig. 106 Whirlpool.

Currents, vortex, rotation, sucking, drowning.

Fire

Fig. 107 Fire.

Heat, cook, destructive, combustion, burning.

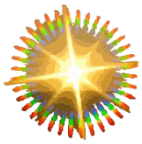


Fig. 108 Solstice.

Rare, cycles, high, low, long.

Fig. 109 Spark.

Ashes, excitement, particle, electrical, stimulus.

Fig. 110 Sunrise.

Morning, colours, daylight, appearance, summit.

Fig. 111 Sunset.

Disappearance, decline, fades, spectacle, evening.

Air

Fig. 112 Bird.

Beak, feathers, vertebrate, secret, shocked.

Fig. 113 Hawk.

Vigilance, advertise, aggressive, prey, wing.

Fig. 114 Owl.

Hoot, nocturnal, wise, tawny, flight.

Fig. 115 Lightning 1.

Clouds, flash, speed, voltage, electrical.

Fig. 116 Lightning 2.

Bright, thunder, rain, discharge, shock.

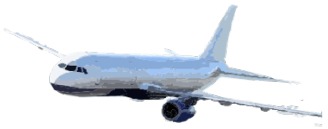


Fig. 117 Plane.

Aircraft, machine, transportation, glide, spiritual.

Aether-Cosmos

Fig. 118 Sun.

Burning, bright, distant, solitary, glowing.

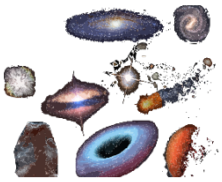


Fig. 119 Stars and galaxies.

Interplanetary, unknown, darkness, ancient, unpredictable.

Fig. 120 Extra-terrestrials.

Foreign, imaginary, futuristic, dangerous, powerful.

Fig. 121 Alien.

Fictional, spaceship, unfamiliar, disturbing, hypothetical.

Fig. 122 Comet 1.

Fast, uncommon, out of nowhere, heavy, geological.

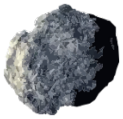


Fig. 123 Comet 2.

Rock, particles, meteor, supernatural, omen.

Fig. 124 Moon.

Stars, craters, celestial, floating, mystery.

Summary

This chapter explores an artist designed art therapeutic visual prototype. The same digital animation program that was used in the workshops with the TYA's was used to help conceptualize and make this prototype. In this prototype I synthesize the body map exercise that uses traditional media, the abstract auto-portrait collage, and the collaged media body map. To do this I did the body map exercise myself and crafted digital objects to create and archive of images that can be re-used (see Figure 38) p. 124. a prototype sketch symbol archive key is included that provides words that relate to the symbols within the archive.

I participated in the body mapping exercise in Flash CS4 using the image archive (see Figure 36 -Flash CS4 Professional screenshot – body map REM 1) p.119 and (see Figure 39 - Digital body map collage REM 3) p.125. I wrote journal entries about my experience of doing the body mapping exercise. As I crafted this prototype, I noticed that I was taking a self-diagnostic approach to my body map. My inclination was first to explore the difficulties and problem areas.

This conflicted with an urge to acknowledge my strengths and to counter the difficult areas with areas that I chose to represent my strengths, using positive imagery to represent these characteristics. The body mapping exercise was more challenging than I had expected.

This digital prototype relates to the next chapter, in that it is a synthesis and a translation of the body mapping exercise that goes through a digital process. To create the badges in the next chapter the TYA's body maps were first digitized with specialized embroidery software and then produced using computerized machine embroidery. In both cases the TYA's body maps are transformed into something new. In chapter 6 the body maps are transported into the fine art context.

Chapter 6: Digital arts-based research in the fine art context

In the summer of 2015, I was invited to participate in an artist residency at the Slade Art Research Centre in collaboration with the Camden Arts Centre. The residency culminated with an exhibition of the work made in the residency. I took this opportunity to bring the digital visual ethnography data and the experimental data I collected from the co-design workshops into a fine art context and to experiment with the change of context from the clinical environment to the art studio, and then to a conventional gallery space. I had the benefit of a studio space as well as dialogue with arts professionals from London giving me unbiased feedback about the data from a fine art perspective. I set up a desk space in the art studios and carefully taped the body maps on the wall of my area so I could examine each one in detail see (Fig. 125) p.152. My space was more like an office than an art studio. One gallery director had said of the body maps that they looked like they were part of a campaign. I became versed in talking about the work to the participants and the visiting artists during the feedback sessions.

The Goldsmiths research student handbook stipulates that the fulfilment of PhD in Arts and Computational Technology requires 'a practical/technological component in a form appropriate to the student's artistic and technical project which shall be the subject of a public display or appropriate form of dissemination' (Goldsmiths University of London, 2017, p. 60). While in residency I engaged in a visual analysis of the body maps that I elaborate on in Chapter 6 and a self-reflexive evaluation of my art practice that I have applied to an artistic and technological form for exhibition. During this time, I carefully mapped out and conceptualised how I wanted to transform the participants body maps into a fine art presentation. I listened to feedback from the other participants and reflected on my own experience with the co-design workshop participants and their art-based data.

I often think about the age group of the participants in my research and what it would be like to be a teenager now in this era of digital visual saturation. I also think about the vibrancy and enthusiasm a large portion of the young people embodied even while they were undergoing very serious medical procedures. One day while I was on the bus, I saw a young man with embroidered badges sewn all over his denim jacket. His presence drew my attention and I made a connection between youthfulness and badges. The badges in themselves were sending me subtle visual messages of rebellion and self-determination;

that this young man was saying without speaking that he belonged to a tribe that was somehow different.

Badges historically have been used to communicate messages of all kinds; they are like miniature billboards or silent visual protest vehicles for political rhetoric. There is also the badge of honour or courage; for example, those awarded for wartime service. The badge functions in the same way that a picture hangs on a wall, perhaps because there is a border on the badge and the image within the border is contained within a frame or on a textile surface to be applied to another surface like denim or cloth. Hordern and Lynch assert that 'embroidery has been a part of our social fabric for hundreds of years. It has been a medium for historical commentary; for homage to ceremonial and religious occasions; for expression of creativity; for utilitarian purposes; or simply for leisure and social contact' (2006, p. 2689). This sighting of the young man with badges gave me the inspiration to create badges from the participants' hand-drawn body maps.

Origins of computerized embroidery

When I formulated the concept of the badge, I had computerised machine embroidery in mind for the production of the artwork. The importance of the Jacquard loom, which was the first programmable power loom invented by the French weaver Joseph Marie Jacquard (1752–1834) in 1804, was a source of inspiration behind the work. The role of the loom in the history of computing is the conceptual foundation for the construction of an apposite discourse between badges and the production and display of an artwork within the specification of art and computational technology. Ganapati supports this view as she explains her understanding of the loom:

> The loom is controlled by a system of stiff punch cards and hooks. Each row of holes punched in the cards corresponds to one row of thread in the design. When the hooks align with one of the punched cards holes, they are able to pass through the hole with the thread thus creating the required stitch to form the pattern. The simplest, repeating designs could fit on a single card (2009b).

The relevance lies with the head of the Jacquard loom, which uses replaceable binary punch cards to control the sequence of operations. The idea of using punch cards to instruct and control a system became the basis of computer programming. Charles Babbage (1791–1871), who is considered the father of the computer, was aware of the functions of the Jacquard loom's punch card system. Babbage built upon the system to design the beginnings of the analytical engine in 1834 and continued to work on it until his death in 1871 (Science

Museum, 2018). He used the same methodology of the cards to provide the input programmes and data for the analytical engine that was a proposed mechanical general-purpose computer. Ada Lovelace, the English mathematician and writer who collaborated with Babbage, published in 1843 what we would now call a computer programme to generate Bernoulli numbers. While Babbage had written fragments of programmes before, Lovelace's was the most complete, elaborate and the first published:

> Lovelace was the first person to foresee the creative potential of the Engine. She explained how it could do so much more than merely calculate numbers, and could potentially create music and art, given the right programming inputs (Findingada, 2018).

For example, in 2009, the BildMuseet at Umea University in Sweden hosted an exhibition, Open Source Embroidery, which explored the history of computing as craft and presented artworks that used embroidery and code as a tool for participatory production and distribution. This exhibition later travelled to San Francisco's Museum of Craft and Folk Art. Dr Ele Carpenter, curator of Open Source Embroidery Group organised this exhibit, which sought to understand the shared philosophy and methods between craft and technology. As a point of departure, she used the Jacquard loom that is considered as the first programmed machine and one that inspired Charles Babbage in his design of the analytical engine. Carpenter asserts that 'open source programmers and crafters may seem like they come from different worlds. Still she believes the communities have much in common' (Carpenter cited in Ganapati, 2009a). She comments that 'If you think about soldering electronics, it is a lot like embroidery and involves threading fine pieces of wire to create an intricate circuit' (Carpenter cited in Ganapati, 2009a).

Carpenter's artwork, 'HTML Patchwork', which was displayed in both of the above exhibitions, is on display at the National Museum of Computing, Bletchley Park, UK. The HTML patchwork is a colourful seven-foot high quilt created by more than 200 needle workers from across the globe (TNMOC, 2018).

This exhibition does not include machine embroidery made using computerised techniques but focuses on hand-crafted embroidery methods and how they are related to open-source software. While my conceptual framework for the badges builds on the similarities with the open-source embroidery group, it forges its own unique relationship with computers and digital technology and participatory arts-based research. The badges acknowledge and work with the materiality of the digital medium.

Bill Wilson, the founder of Wilcom embroidery software company, developed the first industry-specific software for the digitisation of embroidery (*Images Magazine*, 2015). In the 1970s Wilson was doing his master's degree in mechanical engineering in Canada, looking at how to control machines with software. He was offered a number of projects, but the one that grabbed him was an embroidery machine project. Bill states, 'That's kind of novel' (*Images Magazine*, 2015). It was a mixture of electronic design, mechanical design and software. He was introduced to a professor in Canada who was working on computers and embroidery and who invited him to work on a funded project to make something commercial out of his master's project. Wilson was the first person to use computer graphics to do embroidery design. In 1980 he presented the first digitising system to the public. Today he is the author of Embroidery Studio Designing with CorelDraw graphics suite (Wilcom, 2018), which is software for ultimate embroidery and multi-decoration for the customisation of embroidery for professional digitisers, embroidery shops, industry trainers and educators, and apparel decorators. They even have a software program for hobbyists, making computerized machine embroidery accessible to the layperson.

Conceptual layering

These badges make their unique contribution in the digital translation from the hand-drawn body maps by the participants. The new possibilities that computerised embroidery offers for the distribution of artwork is immense. A unique message in the form of a badge can be mass produced and be distributed widely using visual research data. The multidisciplinary, mixed media approach and the theoretical underpinnings make up components of the visual research data used for the production of the badges. This approach contributes to the expansion of the boundaries of participatory art-based research and material-based computer art through this novel art form.

The patient/participant first uses their body as a probe and prosthesis in the posthumanist sense, according to Hayles, in that:

> It thinks of the body as the original prosthesis we all learn to manipulate, so that extending or replacing the body with another prosthesis we all learn to manipulate, so that extending or replacing the body with other prostheses becomes a continuation of a process that began before we were born (1999. p. 3).

The participants then locate, visualise and draw their bodies as autobiographic visual narratives. The narrative is then digitised and rendered through a computerised sewing machine in the format of a badge. The badge then becomes an agent of personally coded

information that communicates their data to the world. This communication style speaks in a hyper-attentive mode (Hayles, 2008). In the posthumanist sense, the participant is prosthesis and the digitising software is the extension and continuation that is used to translate the visual research data that is drawn in the body map. The computer, the software, the participant and their research data and the computerised sewing machine become the components in a human-machine reconfiguration (Suchman, 2007) and or assemblage (Deleuze and Guattari, 1988).

Digital arts-based research artwork at the Camden Arts Centre and MacMillan Cancer Centre, UCLH

In this chapter I place the digital art-based research artwork within the context of contemporary art. The artwork can be viewed as contemporary art in the same respect as the artists described in the previous sections, though it has its distinctions. This artwork distinguishes itself through bridging the clinical research communities and the fine art and computing communities by bringing NHS R&D-approved research into a fine arts residency. Using the lens of a digital arts-based researcher in the clinical environment as well as from the perspective of an artist, the collaborative art piece is inclusive of several different communities, including contemporary fine arts, computing and the medical and academic worlds.

For the culmination of the London Summer Intensive 2015 the artists in residency were given an exhibition of their work in all stages of production. I made the decision to exhibit the badges in unexpected places throughout the galleries. They are small in scale, and I wanted them to have the space to be experienced intimately and individually. If the participant wears their own badge it can be viewed as performative. Although all of the signifiers are within the badge, it is designed to be worn sewn onto a garment such as a jacket or a backpack. The viewer can also imagine the participant wearing the badge while looking at the badge installed on the wall of the gallery.

Guy Noble, the art curator for University College London Hospitals, UK, has acquired the badges within the hospital's permanent public art collection. When I presented the badges to Noble for safekeeping within the collection, he said that they appeared to him as three-dimensional. They are now installed in the TYA cancer ward at the UCLH Macmillan Cancer Centre. It is important to the research that the badges remain within the context in

which they were made. Because the research data was anonymous it allows for a way that the collective voice and experience can emerge.

This collective voice acts collaboratively, echoing without mirroring the tradition of the quilt as a vehicle for expressing identity, storytelling and memorial. This work synthesises historical and contemporary practices of embroidery within a conceptual artwork. The computerised machine-embroidered badge is a bespoke concept made with careful observations and feedback from the TYA participants. I chose to make a contemporary translation that breaks with the legacy of the quilt to mark the transition from the handmade and craft to the novel approach of digital crafting.

Digital crafting can be described as art objects made through a multi-faceted process of hand and digital means, making the object unique to its maker. Digital technologies and skills are giving rise to entirely new working methods, skill sets and consumer products (Johnston, 2015). The singular badges indicate the fierce individuality that millennials assert. The badges are made with the same uniting textile, white PVC textile and a pallet of primary-coloured thread, which speaks about the complex, overly connected digital world that some navigate on a daily basis.

Badges and installation at the Camden Arts Centre

The following pages show installation shots of some of the badges at the Camden Arts Centre London on 29 August 2015 (Fig. 126 -131). The participants produced 39 body maps on paper, and I chose 12 to reproduce with the computerised machine embroidery method.

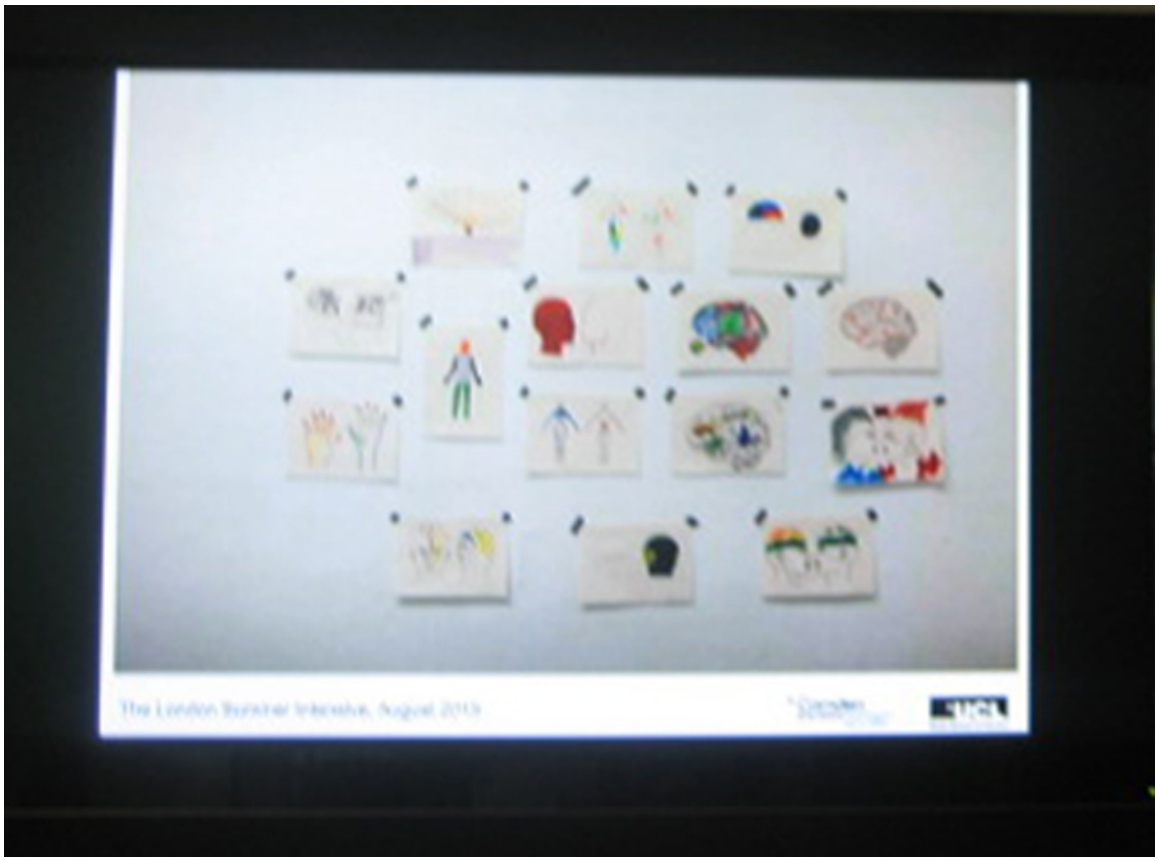


Fig. 125 - Video of my studio wall with selected body maps taped on the wall for analysis (2015).

Fig.126 - Anonymous body map research data rendered in computerized machine embroidery on white PVC textile: gender-neutral outline (2015).

Fig. 127 - Anonymous body map research data rendered in computerised machine embroidery on white PVC textile: head outline (2015).

Fig. 128 - Anonymous body map research data rendered in computerised machine embroidery on white PVC textile: head profile outline (2015).

Fig. 129 - Anonymous body map research data rendered in computerised machine embroidery on white PVC textile: hands outline (2015).

Fig. 130 - Anonymous body map research data rendered in computerised machine embroidery on white PVC textile: brain outline (2015).

Fig. 131 - Anonymous body map research data rendered in computerised machine embroidery on white PVC textile: no outline (2015).

Conclusion

This research and art work produced by multidisciplinary methods speaks about health and wellbeing as well as the lack thereof and the effects on the human body. The artworks communicate the human condition visually and through performative actions in ways that language and text alone cannot express. How this visual vernacular can be used regularly or on prescription for a deeper understanding of the vulnerable body that contributes to health and wellbeing is the aim of the digital arts-based research artwork.

Chapter 7: Evaluation

The aim of this evaluation is to gain knowledge from the research data that I have collected. I present the analysis of the 'visual ethnographic data' (Pink et al., 2018) from this research that was collected using mixed methods approaches (Chapter 2.) that was not included in the previous chapters. The data samples that are included are represented by a selection of narrative, digital and traditional visual art media artefacts.

The analysis is completed within a framework of constructivist grounded theory that I set out in Chapter 2. I do this by conducting data collection and analysis simultaneously in an iterative process. I use comparative methods to systematically analyse actions and processes within the visual data and the observational journaling. I then draw on the findings to develop new conceptual categories leading to inductive abstract analytic categories. I return to following brief inventory of the attributes of constructivist grounded theory throughout this study.

> Constructivist grounded theorists attend to the production, quality and use of data, research relationships, the research situation and the subjectivity and social locations of the researcher. Constructivist grounded theorists aim for abstract understanding of studied life and view their analysis as located in time, place and the situation of inquiry (Charmaz, 2014, p. 342).

With this data that has been collected through an iterative process simultaneously with accompanying narrative analysis of the observational journals I have created new conceptual categories. I accomplish this through drawing on and building upon the data within the earliest category. At the same time using comparative methods of analysis, I am able to synthesize the findings that then progress into the succeeding new categories.

The categories begin with the original digital art interventions and sequentially evolve into the abstract analytic categories that form the digital prototype sketch and prototype tools. The first category begins with digital art and within that section are digital animation and the abstract auto-portrait collage. The next category is traditional body mapping, which is the next iteration and introduced due to its close relationship and shared concepts with the AAPC. The group body map category progressed from the merging of the AAPC and the body-mapping method. Finally, the digital prototype sketch (see Chapter 3.) is the outgrowth of the collaborative data from the aforementioned categories. This sketch is a model of a process that has the scope to mature into future iterations of bespoke

assemblages of computational technology for digital art therapeutic applications. This is elaborated on in the conclusion.

The digital art data presented within this thesis is evidence of the TYAs' interaction with digital art applications. Journaling and narrative analysis that places emphasis on the participants stories reveal the quality of the experience of sharing time in a space of creativity and experimentation with the TYA patients. The following visual research narrative in this chapter was recounted to me through the courageous and inspiring voices and artwork that can be seen and conveyed through observational data in this chapter.

Conceptual categories

Digital art

Digital animation

The images below are stills made in July 2013. They are jpegs taken from animations made by anonymous TYA participants who had never tried animation before. These stills are in addition to the case study stills (see Chapter 2.). The following page is a screenshot of the Adobe Flash CS4 Professional (AFCS4P) user interface (Fig. 132). By using this interface, the participant learns a process about how time operates within the animation. Digital animation is controlled with keyframes on a timeline. There are two types of animation, tween animations and frame-based animations. For this study I use only frame-based animations to create limitations within the activity due to time constraints. AFCS4P also has powerful layering capabilities in the timeline. Because none of the participants that I worked with had tried this application before I chose to limit the animations to one layer to reduce stress and create an achievable learning curve.

The timeline looks like a ruler that represents seconds as a black dot inside a hollow square that corresponds to the numbers above the squares. This can be seen at the bottom of Fig. 132. This black dot is called a key frame. The keyframe contains the information that the user has placed on the white rectangle, which is called the stage. The stage occupies the centre of the grey area called the workspace. The keyframe takes a snapshot, not unlike a page in a flip book.

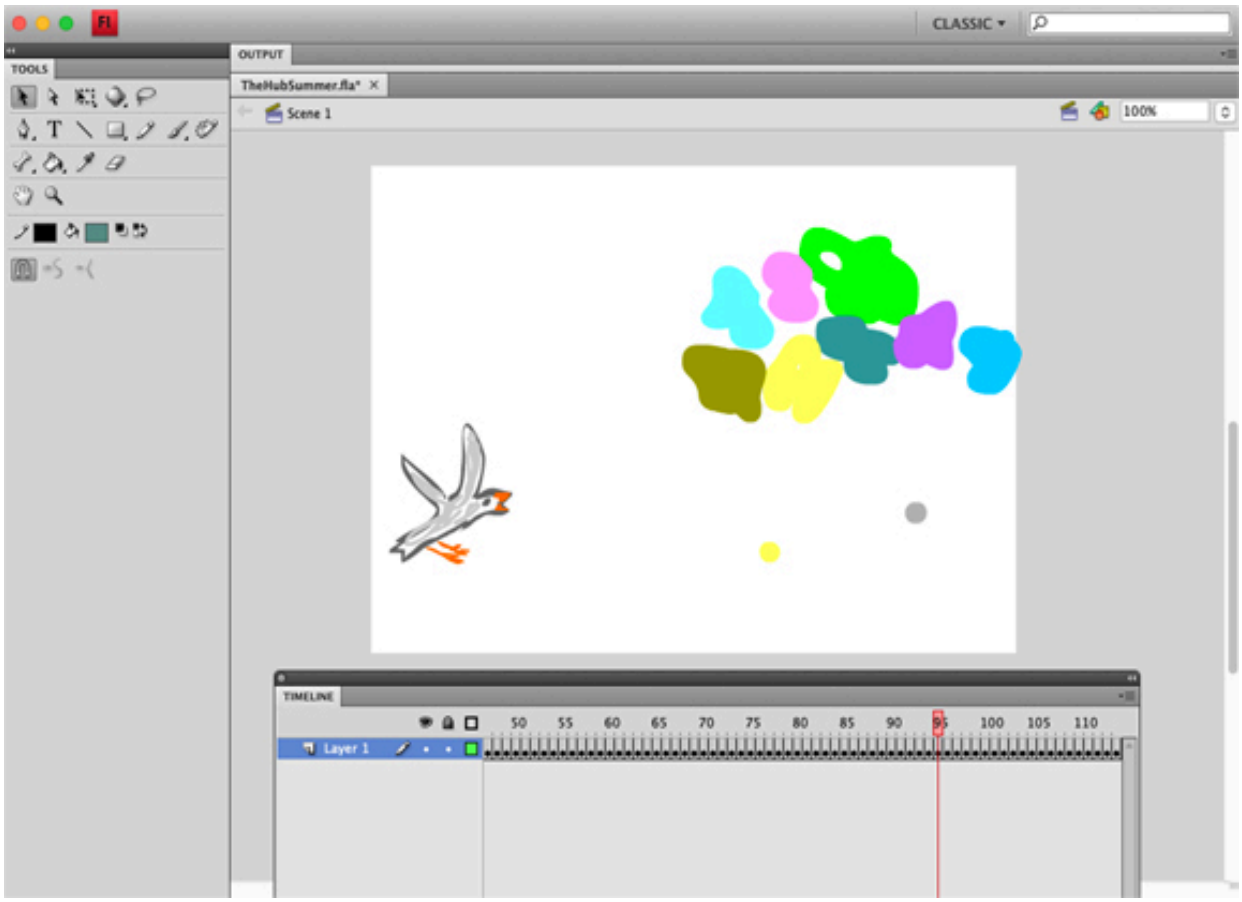

CLASSIC
TOOLS
OUTPUT
TheHubSummer.fla*
Scene 1
100%
TIMELINE
Layer 1
50
55
60
65
70
75
80
85
90
95
100
105
110

Fig. 132

Fig. 133

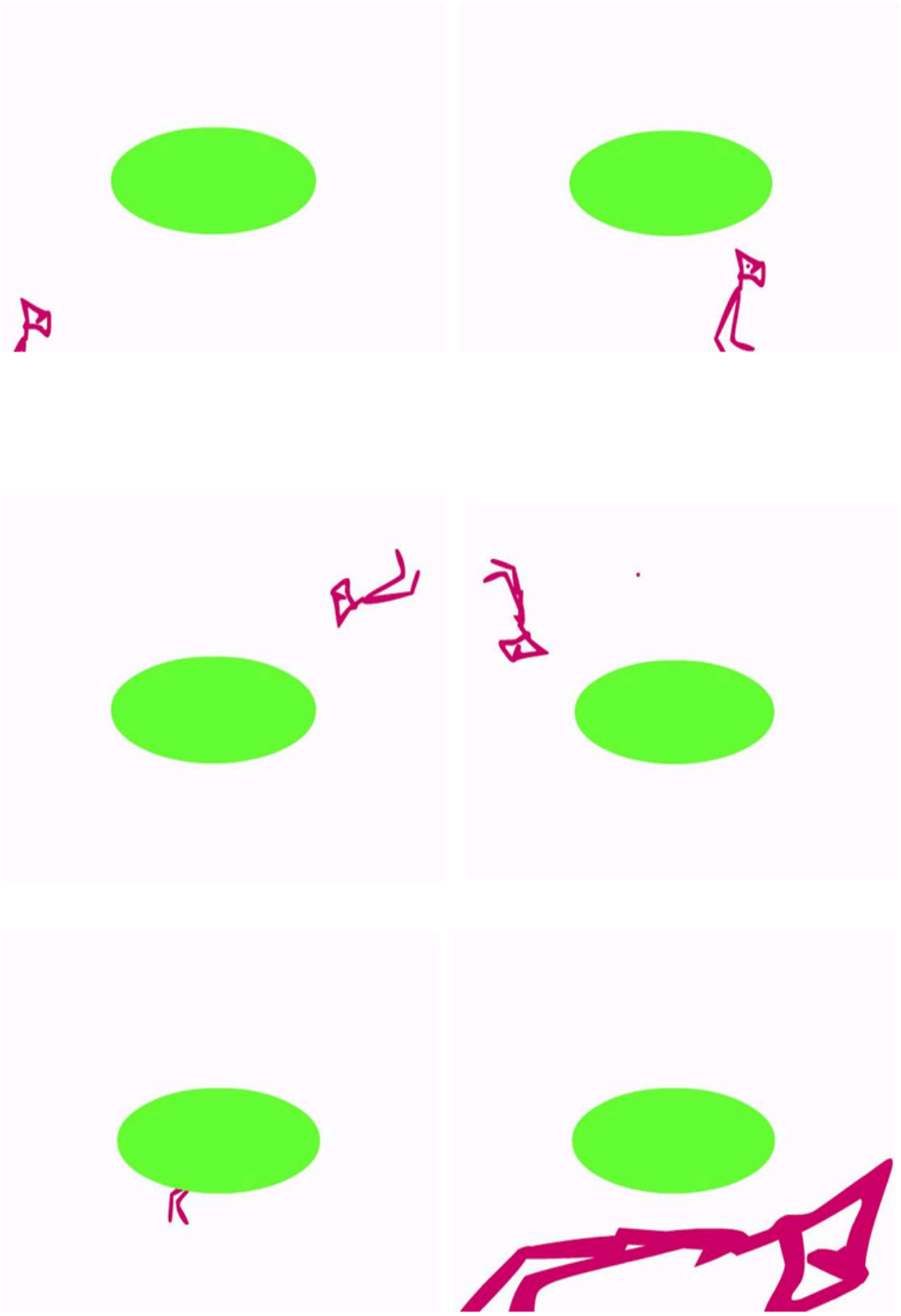


Fig. 134

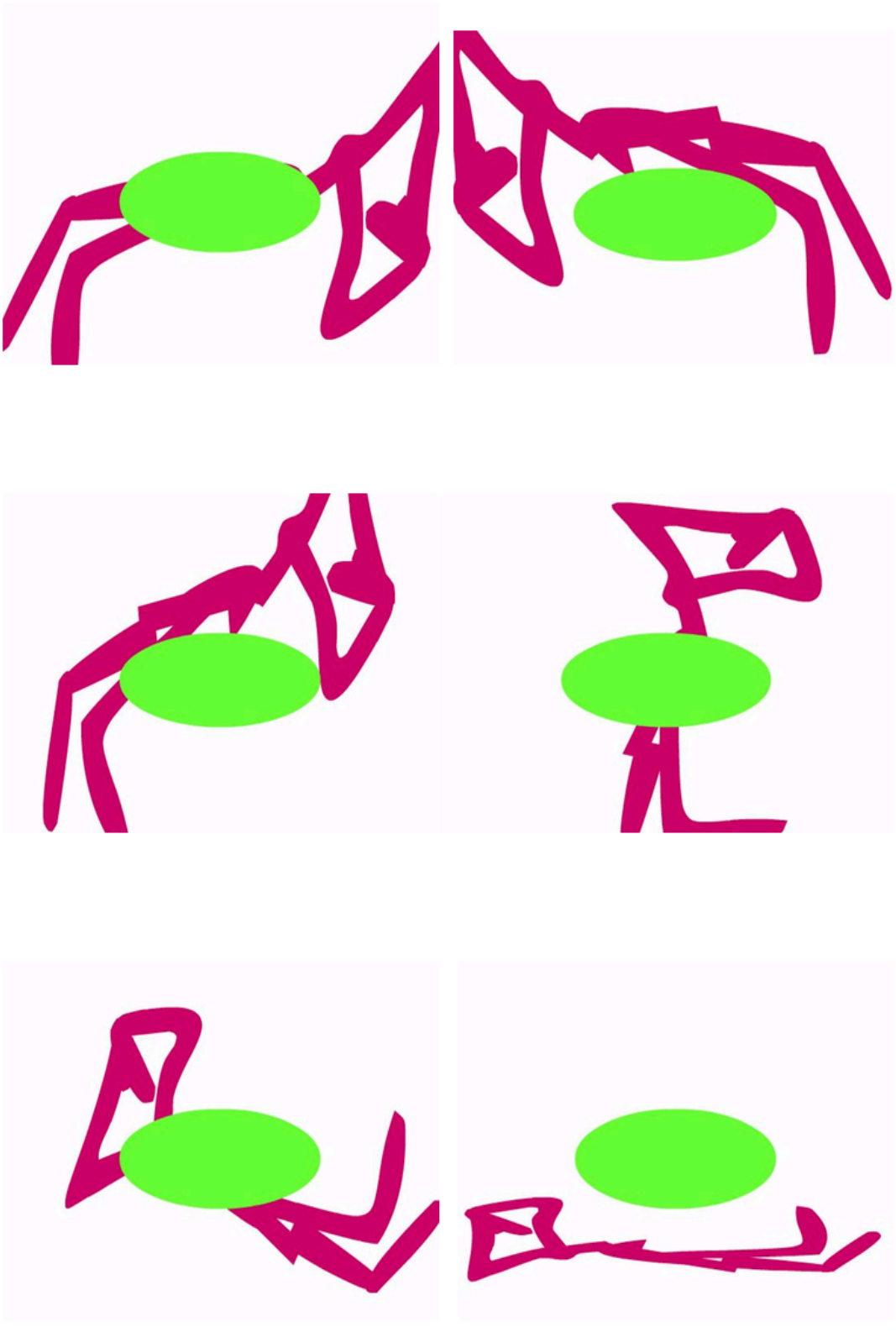


Fig. 135

Fig. 136

Fig. 137

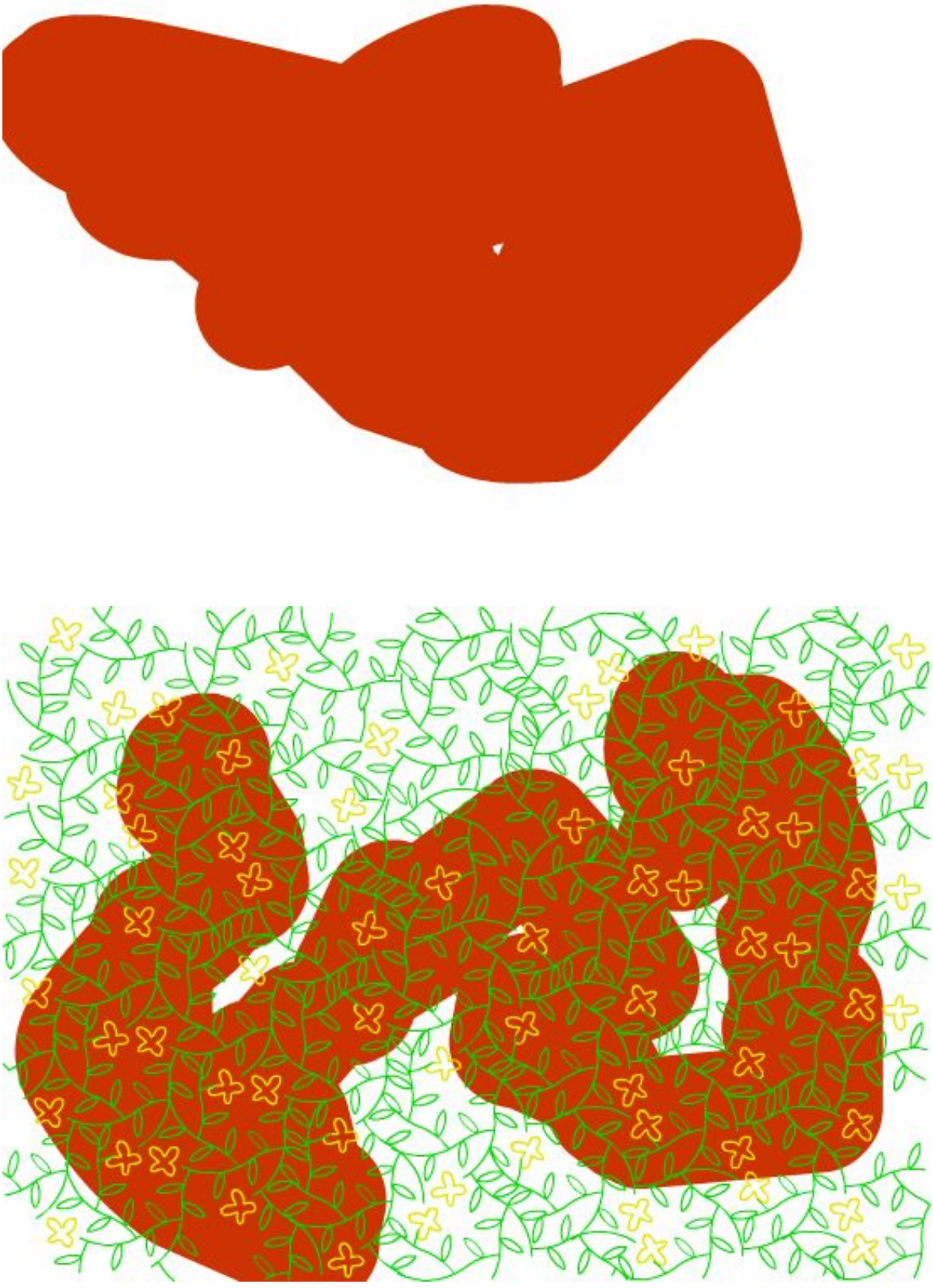


Fig. 138

As seen previously in Fig. 132 p.161 a participant experiments with the paint and paint brushes. The tools that are used can be seen in the top left-hand corner of the

screenshot of the interface. These images are included in the data to show that the workshops are not product-driven but process-oriented. The process that is evidenced by this data is central to the subsequent categories and iterations of this research. The experience of working with the digital tools, familiarisation with time on an animation timeline and creating sequential images within that timeline keeps the participant active.

That being said, the depositing of keyframes in the timeline offers an opportunity for structure through repetition. An affordance of repetition is that it can have a grounding and calming effect on the participants and help to relieve symptoms of anxiety. The participant is able to watch a repeating video loop of what they have created. This has a meditative quality (See fig-7 Bouncing black ball) p.74 and reinforces a sense of accomplishment in the participants. The participants are supported and guided in learning and in the development of skills, confidence and self-esteem. The participants display a sense of achievement when seeing what they can make move.

In the journal entry for *March 31, 2014* (see Chapter 4) p.82 the excitement and optimism participant F displayed evidence of wellbeing in alignment with GIRFEC wellbeing definitions.

Figures 134 to 137 show the participants' process of depicting a sequential visual narrative. Figures 134 and 135 record the stages of a fuchsia figure growing and revolving around a neon green sphere. The exploring figure appears in front of and behind the sphere and grows bigger and then finally lays down beneath it.

Figures 136 and 137 show a mint green citrus fruit in different stages of being eaten or decomposing. In both of these examples the participant showed that they were processing time in a linear way in seconds by creating one image and then depicting in the next instant what will happen next to the images. Figure 138 features a pool of red paint applied with a broad brush. The next frame a decorative stock pattern is layered on top of the red paint.

The process of the participant gaining creative skills and self-expression leads to a sense of achievement and capability. The previous indicators are the most prominent aspects of health and wellbeing that digital animation promotes from my observation and the analysis of this digital data.

Abstract auto-portrait collage category

The section on the AAPC in Chapter 2 is intended to show how this activity fitted into the progression to the decision to include collage type imagery in the digital prototype sketch. In this section I include six AAPC samples from young men (not including one AAPC from Chapter 5) and five from young women (not including the two AAPCs from Chapter 5). I use a comparison method to analyse this data and to reveal the properties that contribute to the emergent categories from the body mapping and collective body map that follow.

Male AAPC samples

This section begins with an AAPC made by a young man (Participant E.E.), who is 19 years old shown in figure 139 p.170. A journal entry for Monday October 6, 2014. can be found in Chapter 1. In this example the use of images in the context of constructing a digital representation of self contributes to a reflexive discourse that is different from what it would be if that person were drawing or painting an auto-portrait. With the computer, the participant is able to access the images on the internet in a reduced time span, in contrast to sourcing images from printed matter and cutting out images manually.

The process of manipulating the images in Photoshop permitted the participant to imagine and embody different temporalities within their digital canvas. Links and connections to aspects of their identity can be made by way of non-linear representation of time and events associated with chosen imagery. For example, E.E. used an actor in the movie Rush to be able to talk about his father. He said the racing car driver looked like his father, whom he does not see very often because his parents are divor

Fig. 139 - AAPC Participant E.E. 2014

In this AAPC the digital canvas is less about skills acquisition and special effects, and more about the personal narrative emerging within his canvas. He showed the dimension of culture, through working with his coping skills and by exhibiting resilience. He did this by using the digital imagery to express and convey a difficult life scenario, which suggests that he felt safe. He was able to access this activity that promoted health and wellbeing, and by doing so he could build resilience through being able to access help when he needed it.

Fig.140 - AAPC Participant D. 2015

Figure 140 is made by a 14-year-old boy (Participant D). The exercise gave him a focus point and he was able to acquire some basic skills. This gave him a sense of accomplishment as well as a space to play. This participant was more interested in how Photoshop operates rather than talking about the images he chose. He said that he was not good at art. This is something that many of the young men said when I approached them to participate. Then when they tried making art on the computer it was easier for them than with traditional art materials. It was possible to connect with young people who did not relate to traditional art materials with digital art media. Being able to reach TYA's through their preferred media is an important finding in that it provides a method to give voice to unrepresented aspects of self. This can be helpful if there are difficulties in communication with medical professionals; the AAPC can add additional clarity to a person's state of being, both mental and physical.

Fig. 141 - AAPC Participant G. 2015

Fig. 142 AAPC Participant H. 2015

Figure 141 was made by a 15-year-old boy (Participant G.) and Figure 142 was made by Participant H. a 17-year-old boy. There is an abundance of playfulness in the previous three canvases.

Recurring images that appear in both male and female AAPC are animals. For males, cars and football related imagery appear frequently.

Fig. 143 AAPC Participant N. 2015

Figures 143 and 144 were made by a 20-year-old male (Participant N) and both feature background scenes from nature. In the image above Participant N uses both figurative and abstract techniques for his auto-portrait (Fig. 143). Figure 144 an intense mystical landscape with an inspirational quote that he wrote. N's resilience and determination came across to me. The addition of text to N's landscape worked well for him, the image and the text punctuating one another making his AAPC more accessible to a viewer.

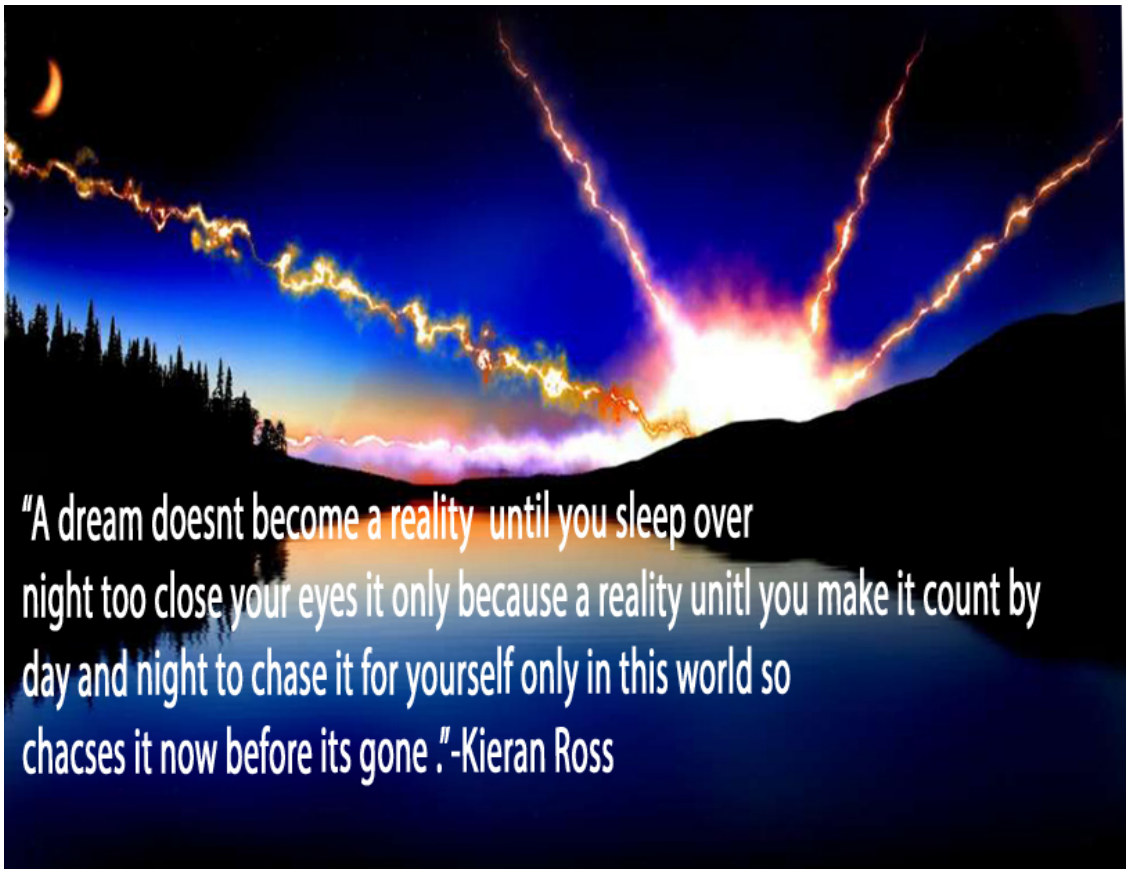


Fig. 144 AAPC Participant N. 2015

Fig. 145 AAPC Participant J. 2015

In Figure 145 Participant J, an 18-year-old male, selected a stock image which looks like a manga graphic novel character. He had some fun experimenting with the rainbow gradient. His AAPC is unusual because he chose a human avatar type character in comparison to the others who chose objects, landscapes and animals.

Female AAPC samples

Fig. 146 AAPC Participant P. 2015

Fig. 147 AAPC Participant P. 2015

Fig. 148 AAPC Participant Q. 2015

Fig. 149 AAPC Participant R. 2015

Fig. 150 AAPC Participant S. 2015

Figures 146 to 150 were made by female participants. Fig. 146 and 147 were made by P, 19 years, Fig. 148 by Q, 15 years, Fig. 149 by R, 17 years, and Fig. 150 by S, 16 years. These AAPCs all contain animals that have been removed from their native environments and placed in a contrasting landscape. These are similar to the AAPCs made by the male participants in that they are all fantastical and imaginative.

The AAPC has similarities in common with body mapping in that it is used as a research method to collect visual data. However, it differs from body mapping in that the process includes the computer and uses it to craft abstracted images for self-representation. The presence of the computer has to be considered throughout the analysis of this visual research. Turkle asserts:

> Computers are more than screens onto which personality is projected. They have already become a part of how a new generation is growing up. For adults and for children who program, play computer games, who use the computer for manipulating words, information and visual images, computers enter into the development of personality, of identity and even sexuality (1984, p. 21).

For the TYA's that have regular access to a computer, tablet or smartphone, their most used device can be viewed as a companion and an archive of digital objects that contribute to the formation of these young individuals.

The following AAPCs take on a more literal and figurative approach. Both Participants T and U filled their canvas with an inventory of objects that stand in for aspects of their identity. There are some adherences to traditional gender stereotypes within the male and female comparative categories. T and U's AAPCs contain female gendered images such as coral manicured fingernails, hearts and high heeled boots. For the males it is cars and football. I did not encourage or make gendered suggestions about how to choose images.

Fig. 151 AAPC Participant T. 2015

Fig. 152 AAPC Participant U. 2015

After working with the AAPC for several years I found that the TYA population work with digital images in a fluent way that is characteristic to some millennials who use digital devices regularly. This reflects the findings of Wood:

> Portable digital devices with access to the Internet enable art therapists and clients to summon up important aspects of the client's life world during sessions. For example: seeing street view maps of significant places; finding photographs or images for collage… (2015 p. 7).

The TYA's connect with and can communicate through found digital images to assist in the creation of personal narratives. That being said, I wanted to find a method that could facilitate dialogue directly with their embodied experience of cancer treatment. The next step would be to transport the TYAs' digital identities into an embodied narrative.

Traditional media body maps

In this iteration I decided to use the body mapping visual autobiographical story telling method that I set out in Chapter 2. I did this with traditional art media because I wanted to reach as many participants as possible. Traditional materials could be used at the bedside and multiple people could participate at the same time so there were not the challenges of managing different levels of digital literacy and resistance amongst participants. In the next section I include samples of the body map visual data, excluding the body maps included in chapter 5.

The body maps are divided into groups that share the same outline. Within the groups I compared and contrasted the individual approaches that each participant applied to their body map.

Traditional media body maps: face front back

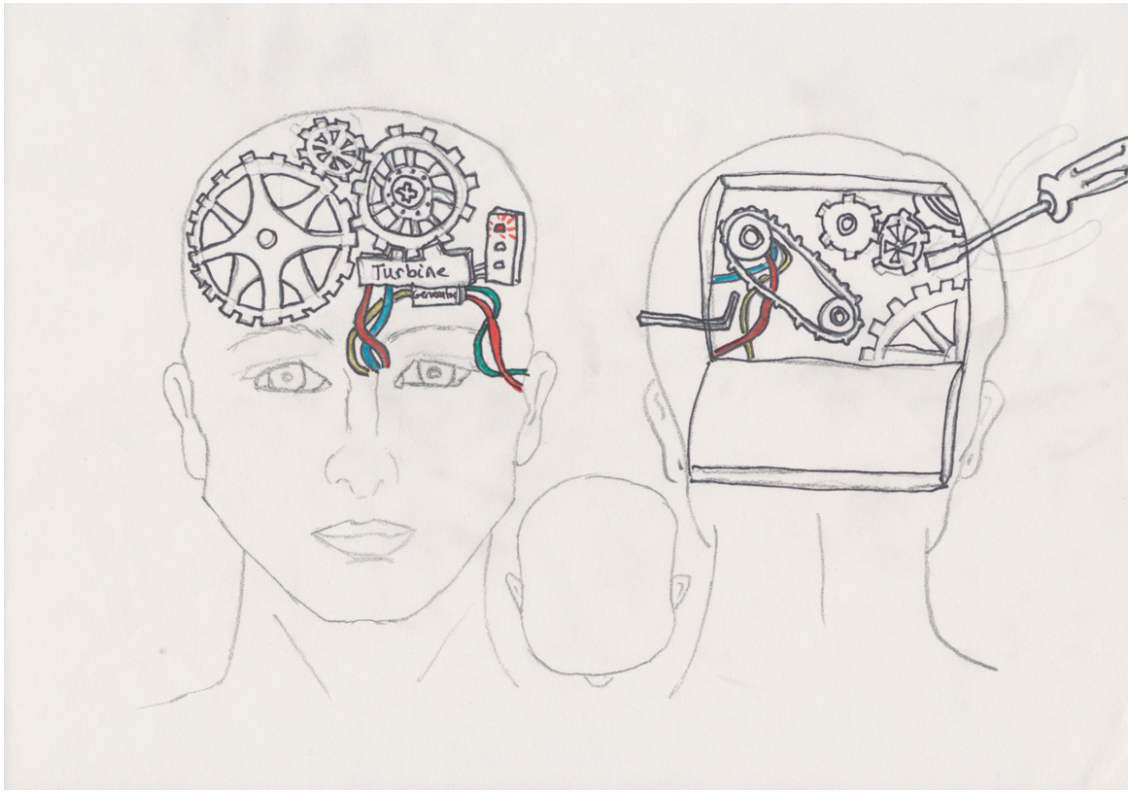


Fig. 153 Face front back, anonymous participant 21/05/15.

Fig. 154 Face front back, anonymous participant.

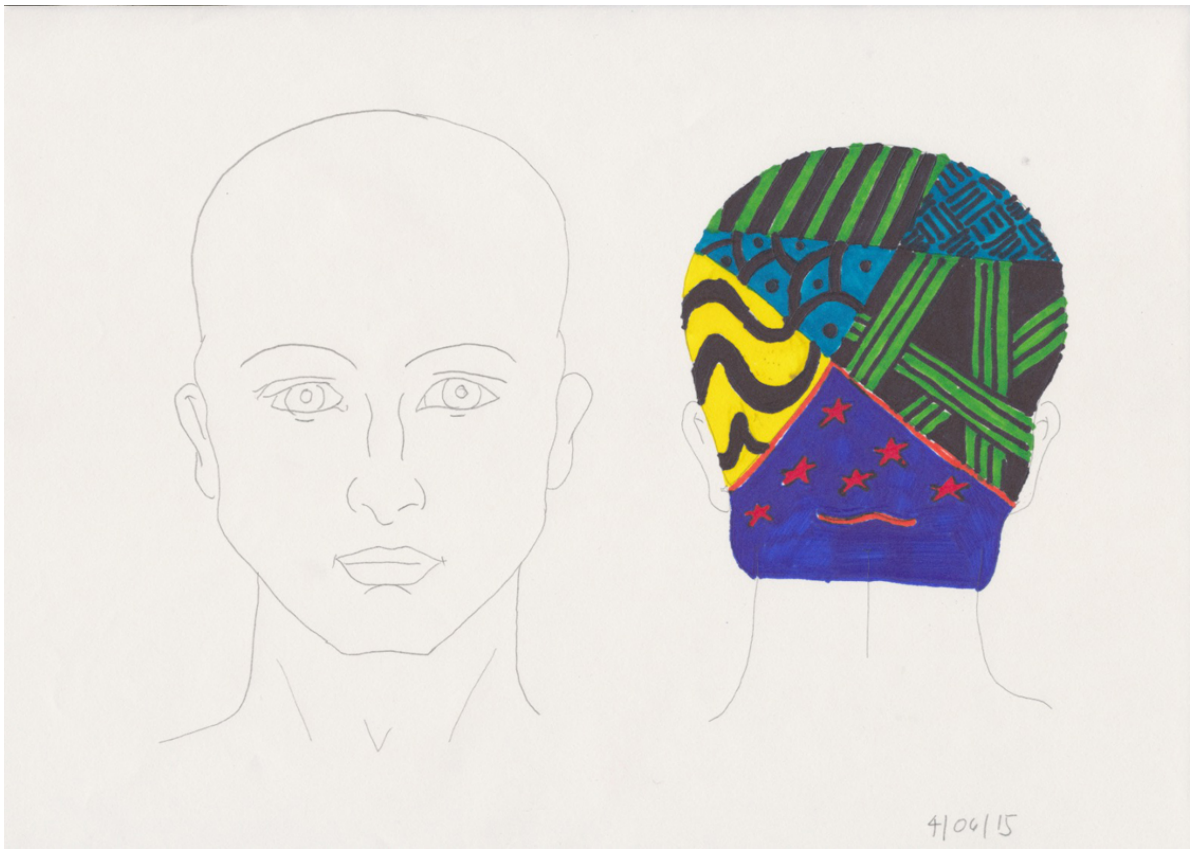


Figure 155 Face front back, anonymous participant

Fig. 156 Face front back, anonymous participant 2/7/2015

In the face front back figures, the first two figures illustrate in a straightforward way how the participant felt in the moment that they made the body map. The maps convey a state or feeling in their body. In Figure 153 the participant has drawn the inside of her head as a machine with cogs, wheels, electrical wires and the word 'turbine'. There is a flap in the back of the head that opens up. There is a floating screwdriver and an Allen key tinkering with the machinery in her head. She is able to express the experience of being worked on or being fixed like she is a machine.

The young man who made this body map in Figure 154 said that the chemotherapy made his head and face feel like it is cracking open. He conveys his discomfort is a figurative and literal way.

In Figures 155 and 156 the participants took a similarly decorative approach in comparison to the aforementioned body maps that appear to be literal. In Figure 144 the participant has dressed the back of his head with a colourful tribal design reminiscent of tattoos that are typical of many young people in contemporary society. In Figure 145 the participant has used red hatch marks on the head and face area and a band around the head to suggest injury. There is positive symbology in the flower with musical notes and a medical inventory of a hypodermic needle and pharmaceuticals. She drew a monopoly game board and a puppy dog. This body map has commonalities with the AAPC in that she brings in several different reference points that express her identity, whereas the previous body maps maintain self-expression within the boundaries of the face front back outline and focus on an embodied medical experience.

Double profiles

The profiles of this body map face each other offering the participant the opportunity to self-reflect on their two sides or if they can identify a relationship between the two faces (Fig. 157). This figure made a strong impression on me through the participant's capacity for self-reflection and therefore self-expression through his solid red profile. He said that it is all red because he gets very angry. He paid a lot of attention to the strokes and was careful not to leave any white gaps. He made the decision not to complete the left-hand side but drew instead a red gesture to mark the profile. This also emphasises the power of his experience of heat and anger.

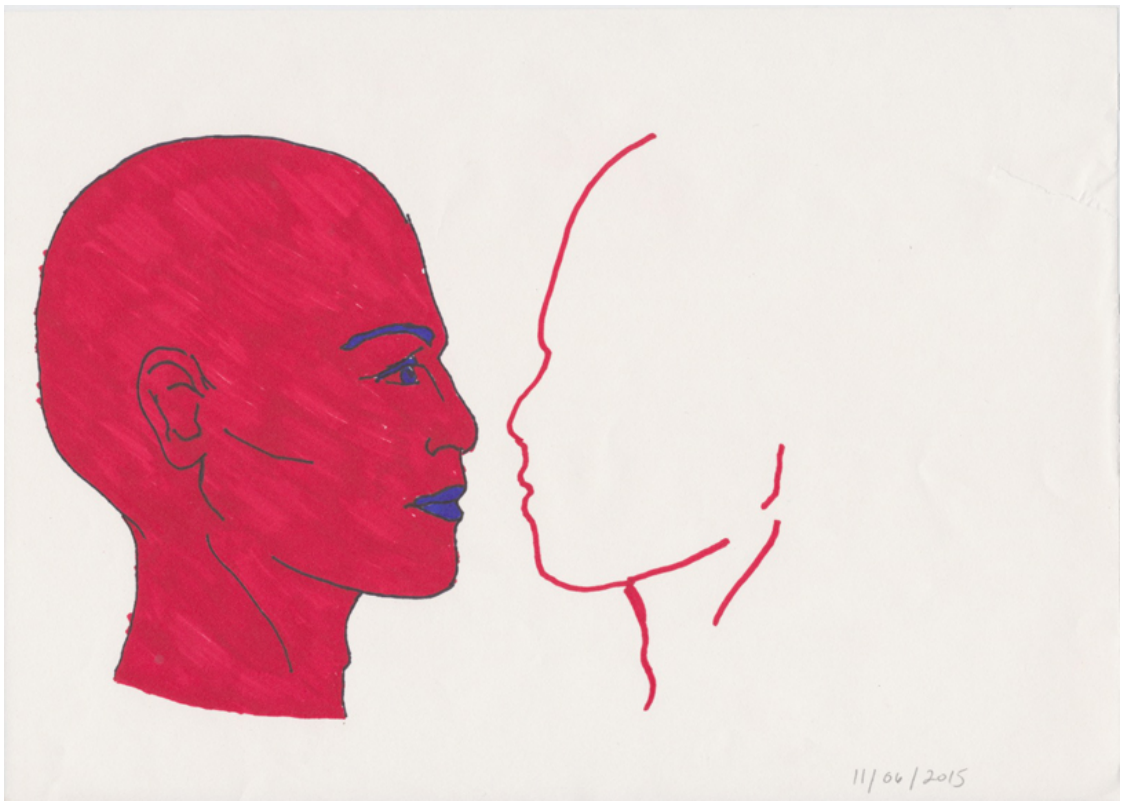


Fig. 157 Double profile, anonymous participant 11/06/15

Figure 158 is an interesting image of two characters that look part Native American Indian and part future fantasy. One is all red with red waves around the neck that makes the connection to fire and the other is all blue with blue waves around the neck, connecting to water. There is a red and black rectangular flag between them. They appear to be of the same status, neither is stronger overpowering the other. There is a yin and yang expression to these two faces, or perhaps a recognition of opposites as in hot and cold.

Figure 159 makes use of language and the dark and bright side of cancer and how they are cyclical. She uses the left profile to release the negative emotional and physical experiences through single descriptive words like 'frustrated' and 'death' with double underlining to emphasise the impact of the words. I can picture the participant reading the body map as if it was spoken word poetry. On the right side she metaphorically beats cancer with a cartoon 'pow!' and words like 'peace', 'Allah' and 'holidays'. There are arrows that indicate that one side flows into the other and the space in between insists on standing up and never giving up. In these two profiles the participant acknowledges difficult feelings and sensations and found optimism in the same body map. These body maps are evidence of self-reflection in the participants, which is a prominent factor in health and wellbeing.

Figure 158 Double profile, anonymous participant

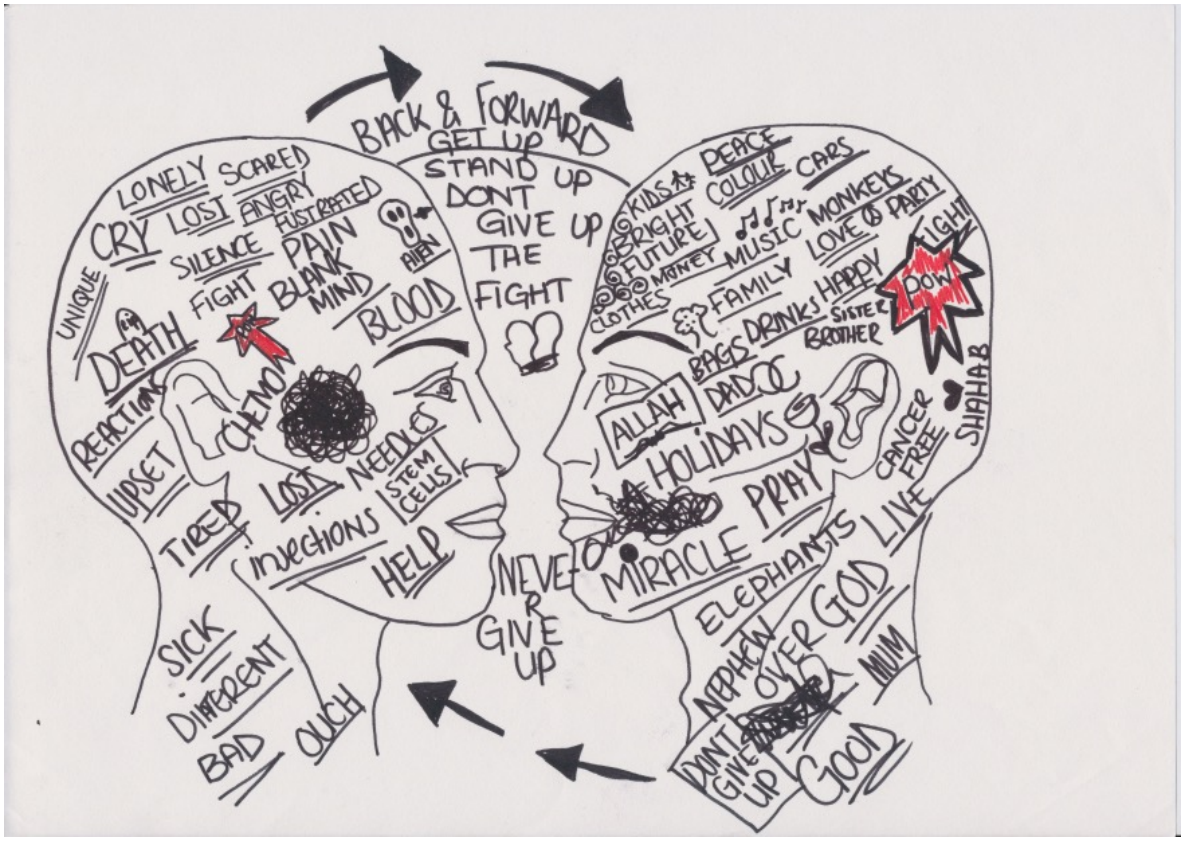


Fig. 159 Double profile, anonymous participant

Brain outline

The brain outline was one of the most popular outlines amongst the young men and women. Those that took a figurative approach chose representations of particular aspects of their life. The brain acted as a place to make an inventory of things, people and places that are significant in their lives. For example, in Figure 160 the participant drew small colourful symbolic representations of cakes, chocolate, clothes, college, travelling, family, her hometown and the Teenage Cancer Trust. These drawings look like they could be emojis that people use to express themselves in shorthand in text messages.

At first glance the colours made me think that these representations were all positive things in her life. The hearts around her family imply love, though the other representations do not give any further details of the story within these locations. Do they speak about situations that cause stress or optimism? For now, they have been placed in the map and can be a starting point from which the participant can begin to explore her health and wellbeing, which could encourage a process of self-reflection.

Figure 167 specifically pinpoints on the cerebellum the origins of bad things, which the participant has labelled as 'chemo' and 'cancer'. The rest of the brain contains aspirations related to money, such as a Range Rover, holidays and being with loved ones. Some of the participants drew patterns on the outlines. One participant drew soft fluid different coloured wavy lines in sections (Fig. 161). Within the cerebellum the word calm is written. The drawing sends a message of calm.

Figure 165 was drawn by a patient's father. He was very open and enthusiastic about participating. He said that he was an electrician. The lines and designs in his outline look like the thin coloured wires that are used in electrical work. He had an uplifting attitude and was happy with his drawing.

The outlines with the patterns drawn within them do not offer a literal narrative but one that marks time and quality of focus on a specific area of the body. The outlines that use text communicate specifically and give objective information within the visual narrative; for example, in Figure 168 the participant inserts language in expressive bubble letters to fill up the reticulated folds of the brain. Other parts of the text are written in smaller letters. Hugging the folds of the brain are descriptive words such as 'Lebanon' and 'kibbeh' (a popular Middle Eastern dish mainly found in Lebanon). The words 'love' and 'sun' are placed close together, evoking comfort and pleasure.

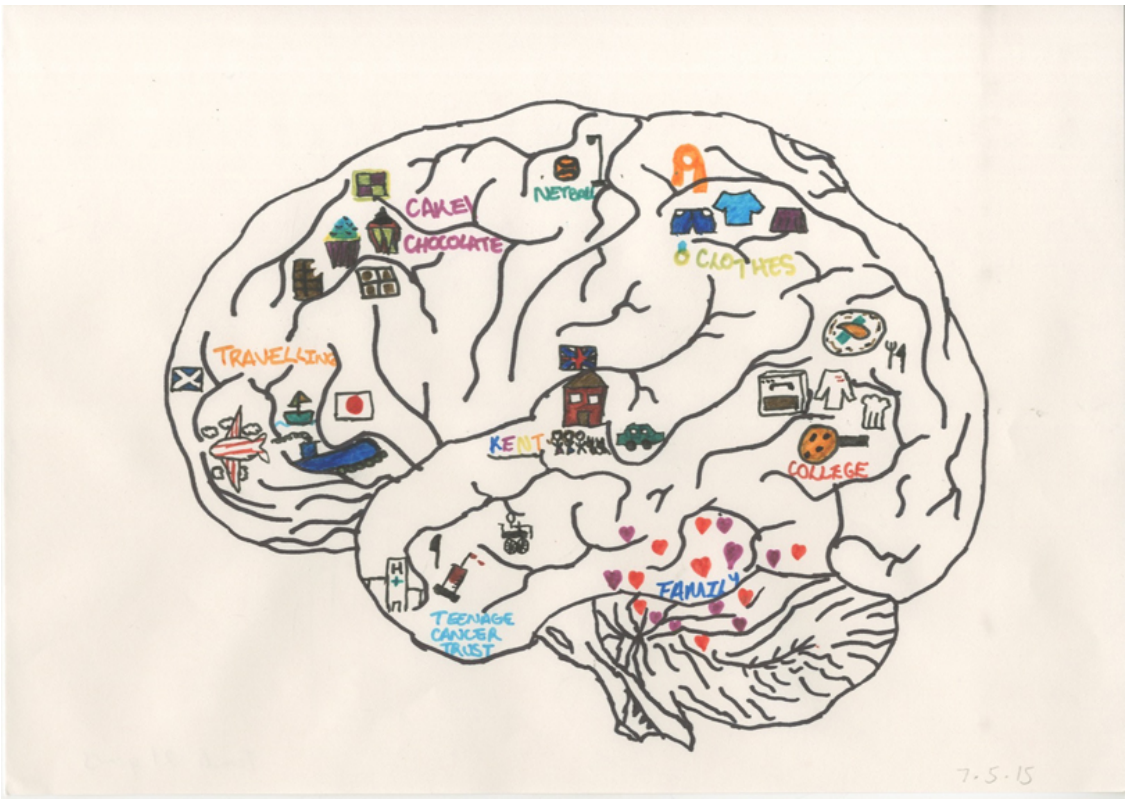


Fig. 160 Brain, anonymous participant 7/5/15

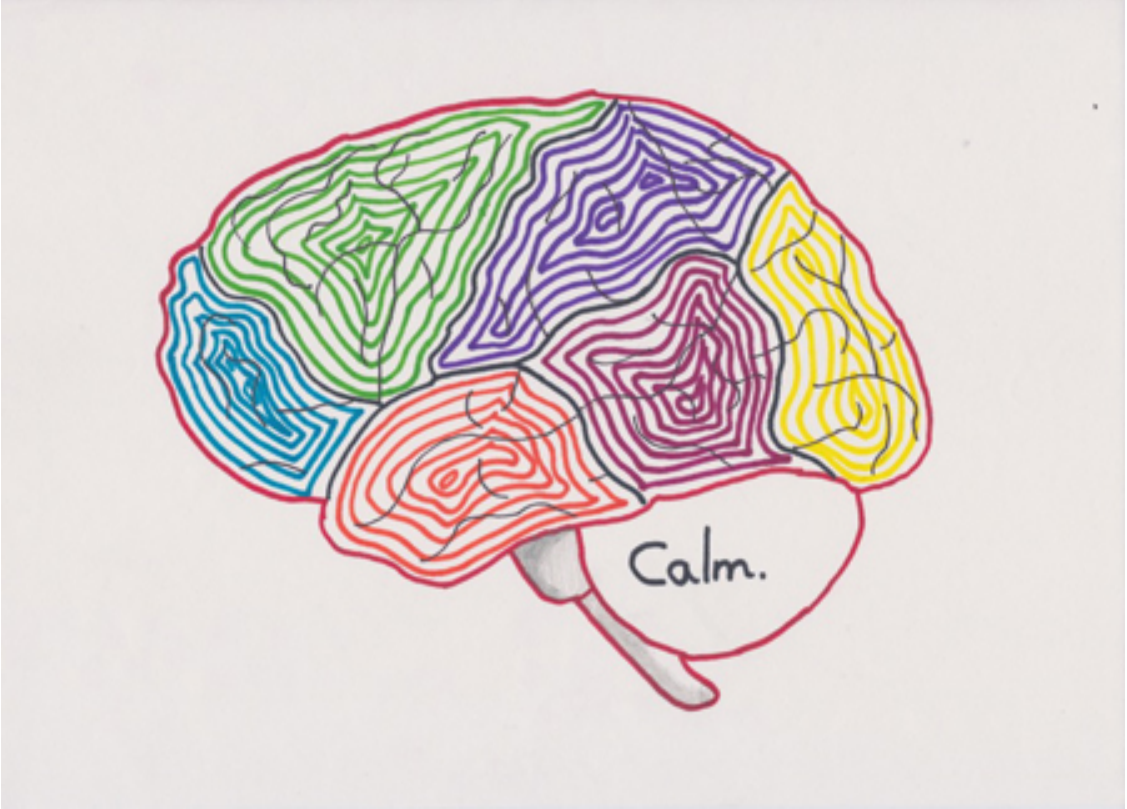


Fig. 161 Brain, anonymous participant 7/5/15

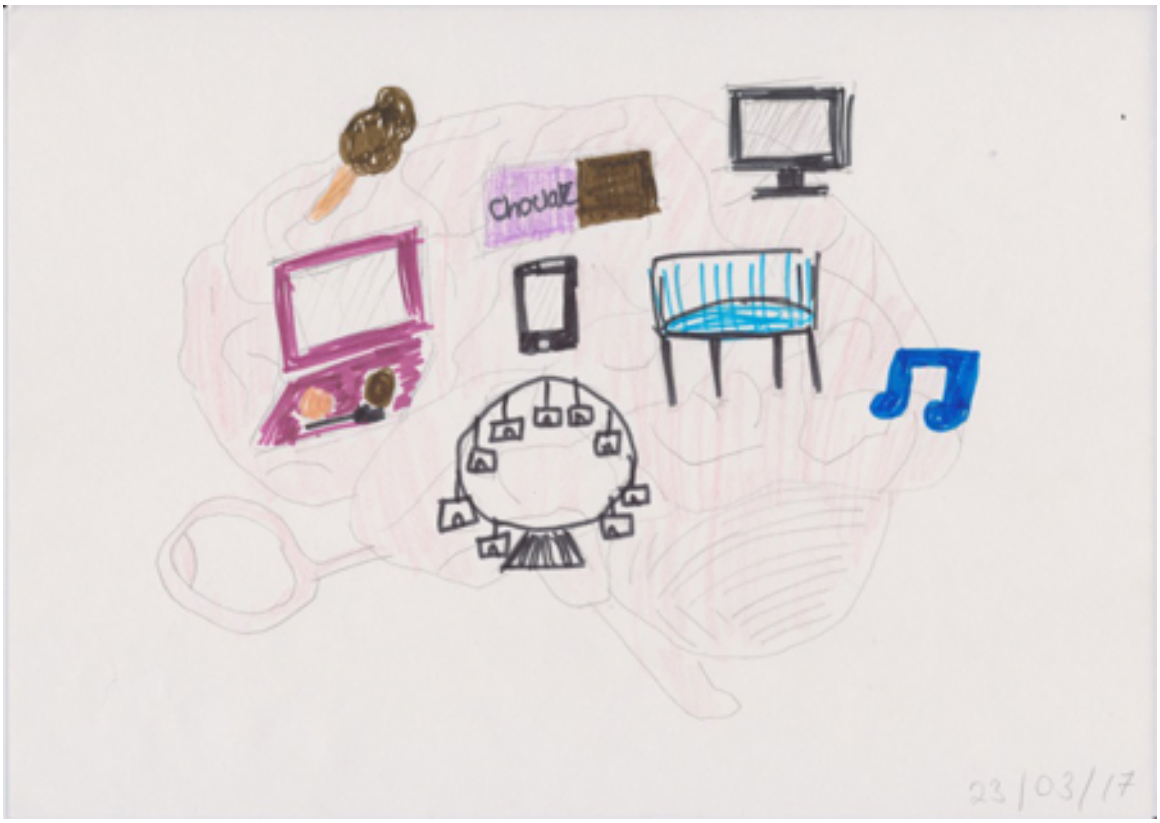


Fig. 162 Brain, anonymous participant 23/03/17

Fig. 163 Brain, anonymous participant 23/03/17

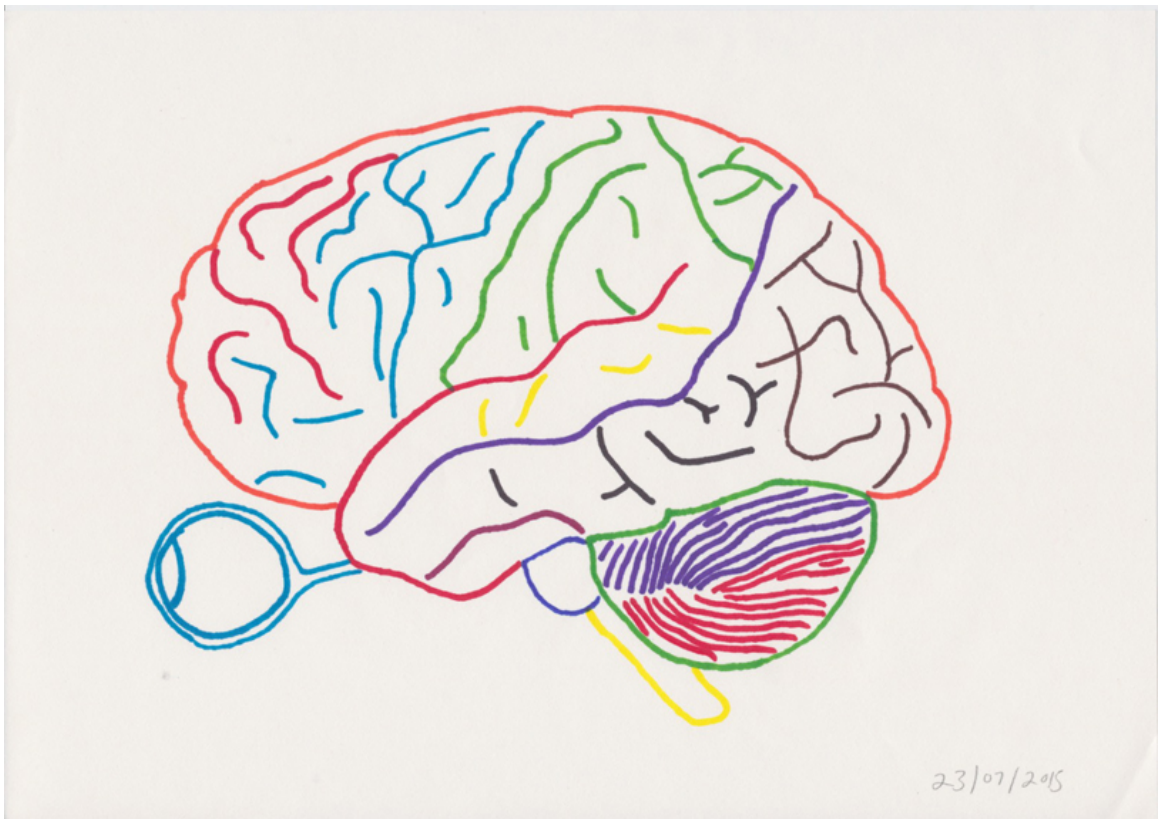


Fig. 164 Brain, anonymous participant 23/07/15

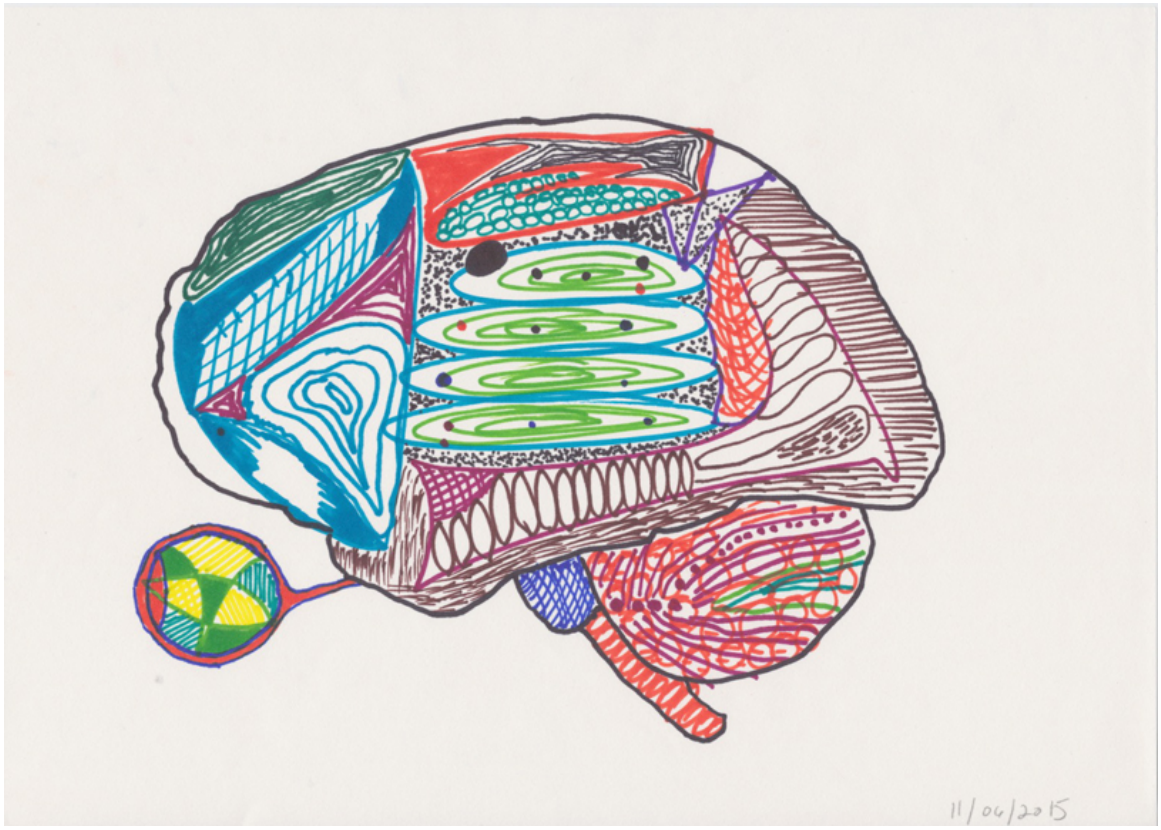


Fig. 165 Brain, anonymous participant 11/06/2015

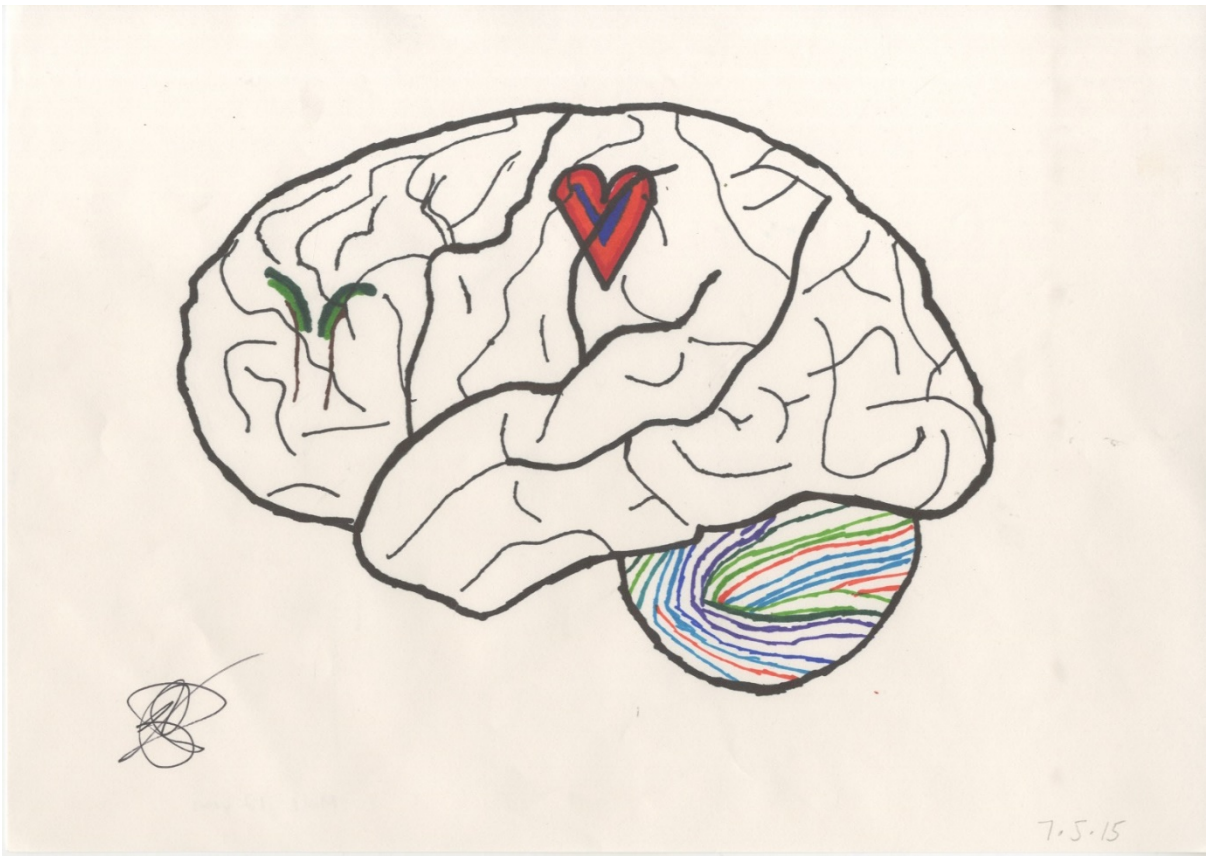


Fig. 166 Brain, anonymous participant 7/5/2015

Fig. 167 Brain, anonymous participant 7/5/2015

Figure 168 Brain, anonymous participant 2/7/2015

Female

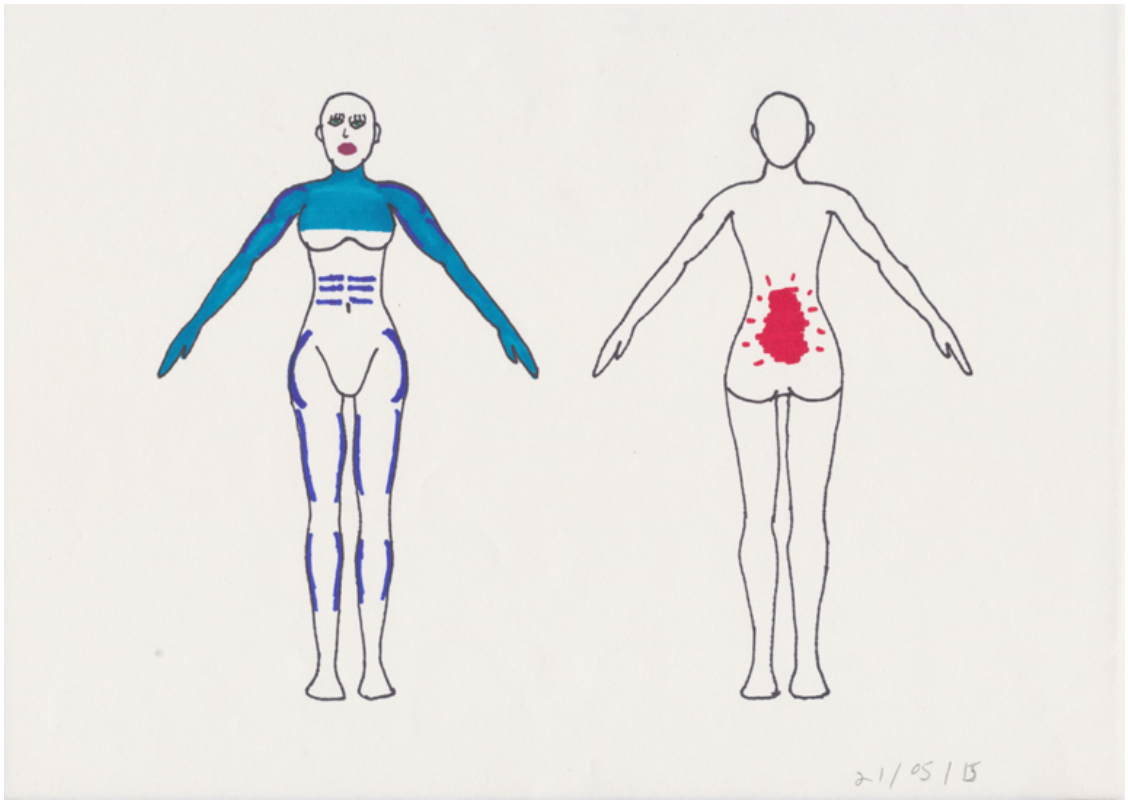


Fig. 169 Female front and back, anonymous participant 1/5/2015

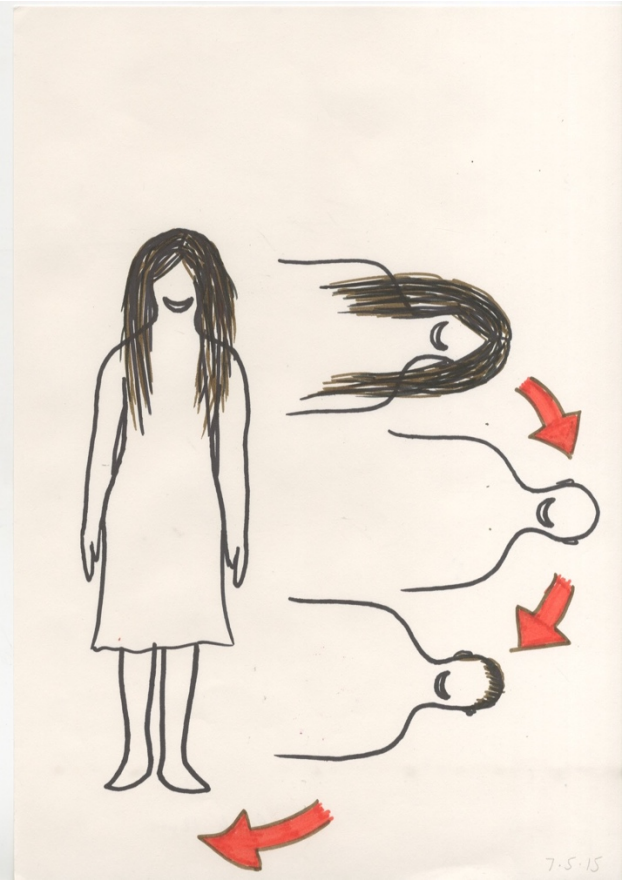


Fig. 170 Female front and back, anonymous participant 7/05/15

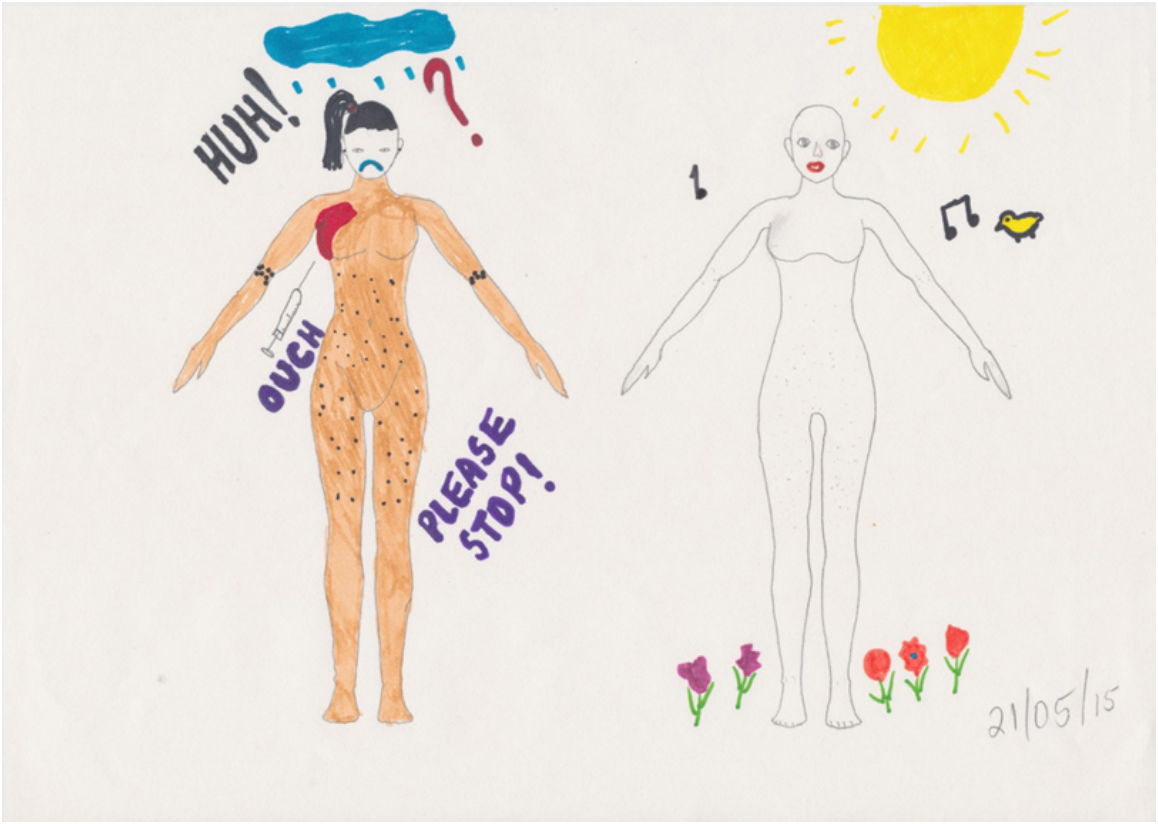


Fig. 171 Female front and back, anonymous participant 7

Fig. 172 Female front and back, anonymous participant, part 1. 2/7/2015

Fig. 173 Female front and back, anonymous participant, part 2. 2/7/2015

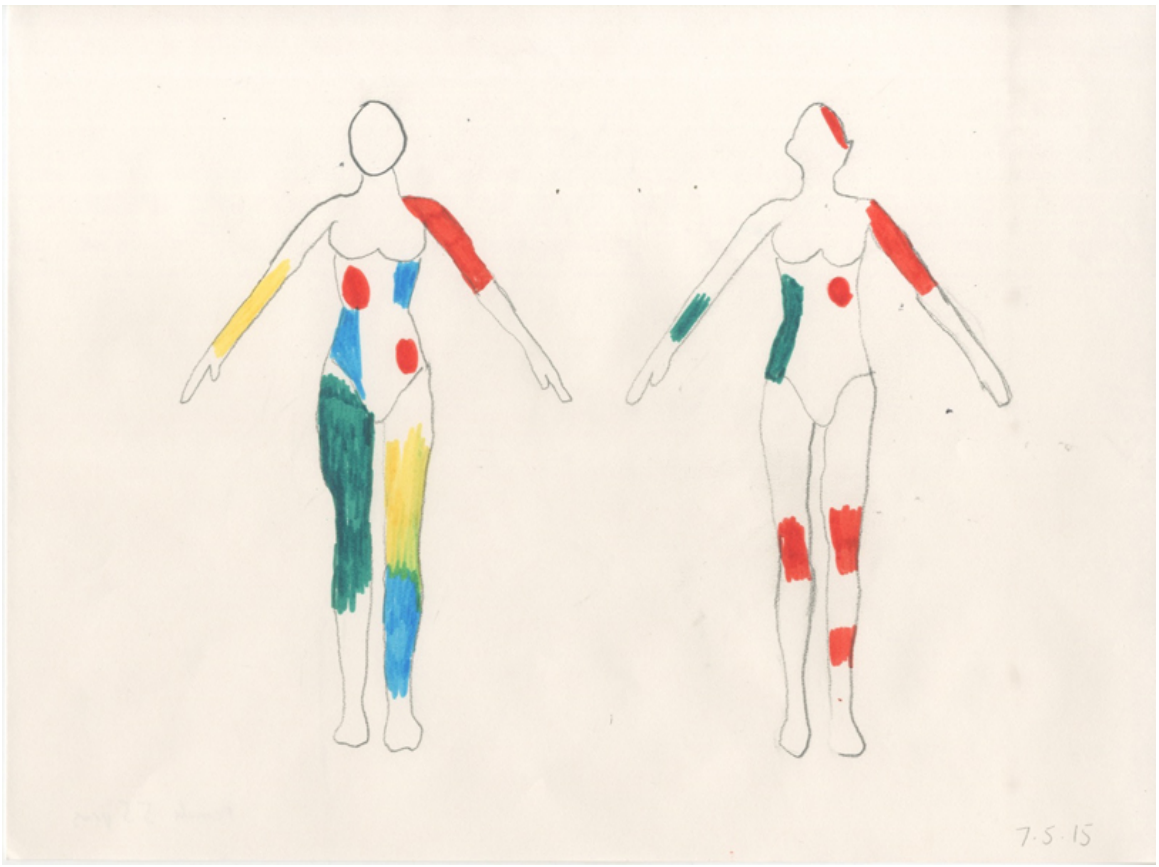


Fig. 174 Female front and back, anonymous participant 7/5/2015

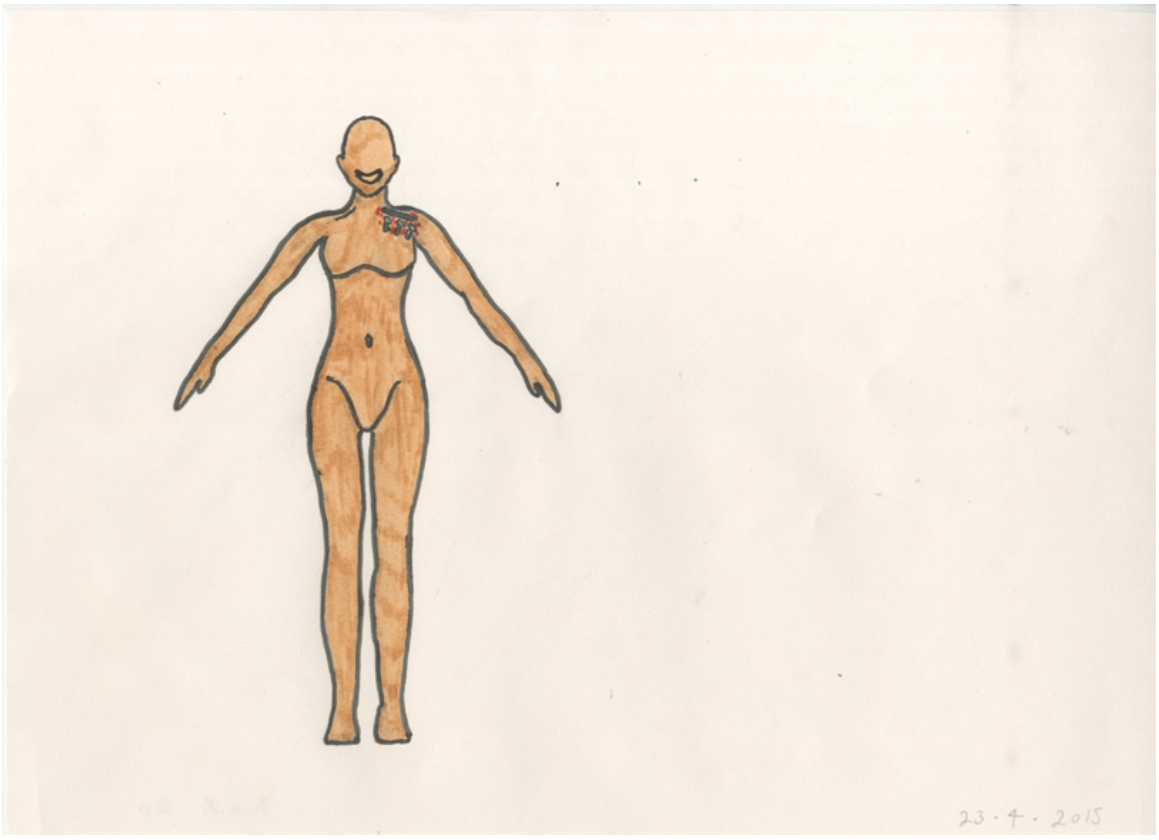


Fig. 175 Female front and back, anonymous participant 23/4/2015

Figure 176 Female front and back, anonymous participant 22/7/2015

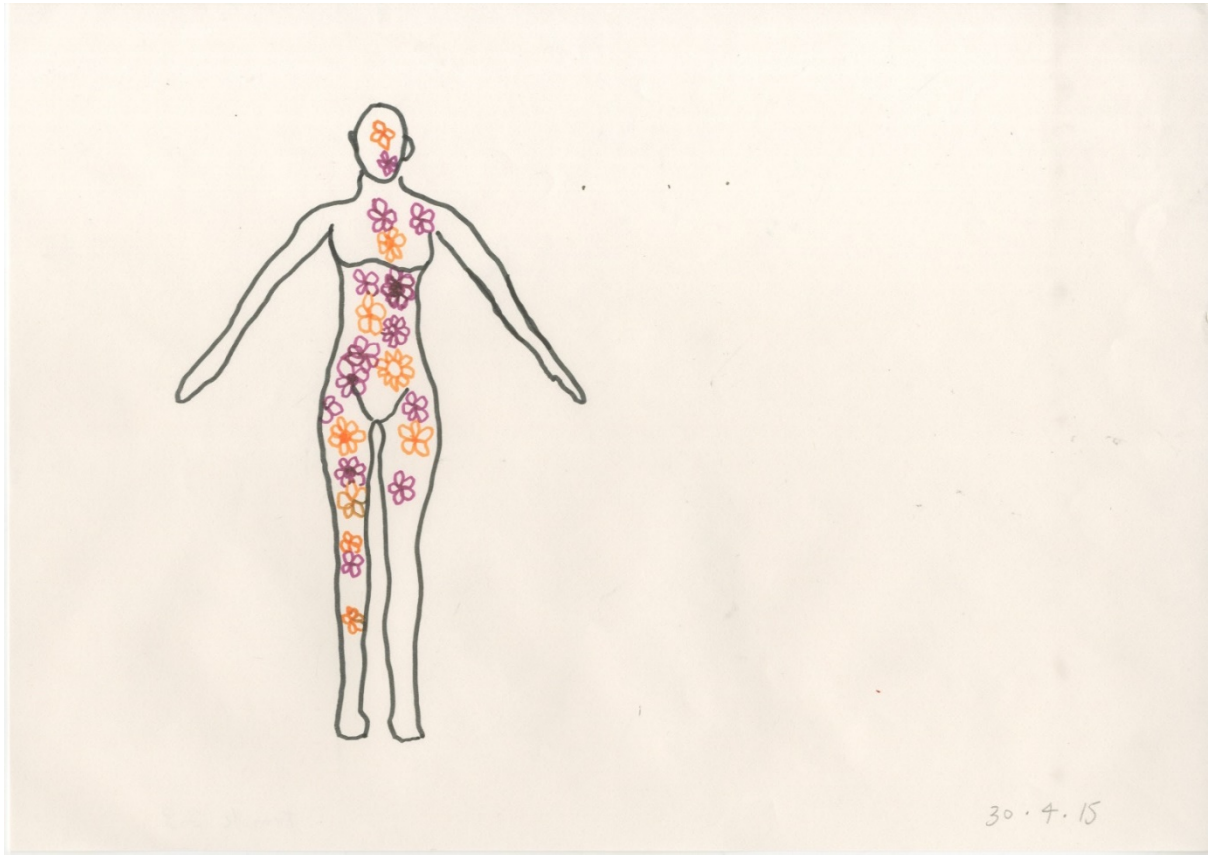


Fig. 177 Female front and back, anonymous participant 30/4/2015

Figure 178 Female front, anonymous participant 4/6/2015

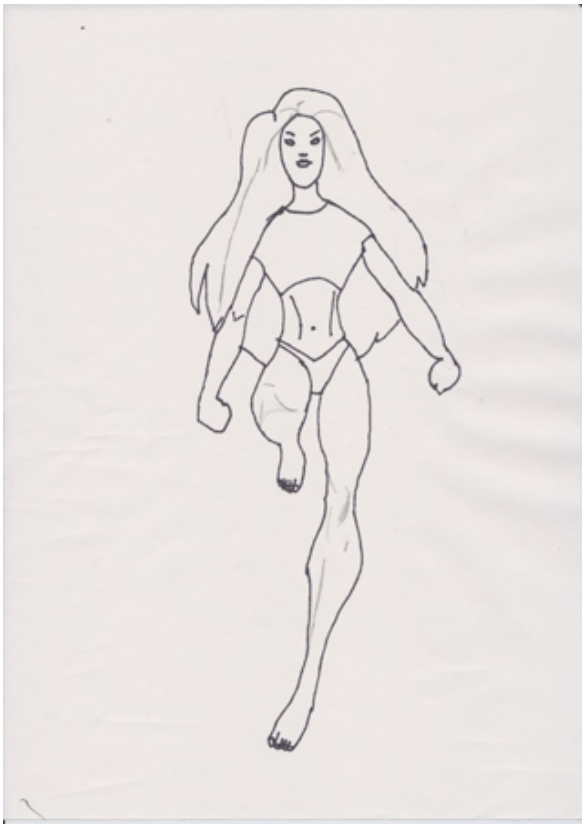


Fig. 179 Female front, anonymous participant 4/6/2015

Female full front and back body maps

The full body maps were chosen only by females; no males chose to do the full male body map outline. Figure 169 was made by a play specialist. In conversation she told me that she was in a bad accident when she was a teenager and broke her back and now suffers from chronic back pain as indicated by the red compressed lines with dashes surrounding the area. The blue arms and neck indicate that she is stiff in those areas.

Figure 170 serves as an educational model of the cycle of hair loss that cancer patients experience through chemotherapy. This participant was Muslim and wears her hair covered and was concerned about drawing an image of herself without a hair covering. She asked for and received her mother's approval. She added a smiling face to each image in the cycle.

Figure 174 was made by a mature aunt of a patient. She traced the front twice instead of showing the back side. In the twin images she drew sections of the body in different colours. She talked about how she could see different colours like auras on and around her body. While drawing her body map she talked continuously about her life and the different people in her family who had suffered from cancer. She did not say what the colours meant for her, only that she felt better after drawing on the body map.

In Figure 175 the participant drew tiny screws on her left shoulder in the place where she had previous surgery. The incision is still open, and blood is visible. She filled in the body with a flesh coloured pen. Several other participants also used the body map to document medical procedures from the past. Like scars, the representations of the surgical screws or medical hardware are a part of the participants' embodied representation of self. This figure also has a broad smile.

The participant who drew Figure 171 also chooses to draw a second forward facing figure. In the first figure she draws multiple punctures in her skin and a hypodermic needle. She draws a sad face and the words 'huh!' 'Ouch!' and 'please stop!' in bubble letters. A cloud with rain coming down on her head is above. In the twin version there is a sun in the sky, her body is unmarked and there are red lips and wide eyes on her face. Flowers grow at her feet and there is a little bird singing at her shoulder. The word 'huh' communicates a lack of understanding of the situation that she is in. The pain that she expresses and the polite insistence for it to stop are expressed in this figure. The counterbalance to this image is one that is free from the marks of medical treatment. This is the sunny place for her. She has found a place of optimism through and in her drawing. Her

situation could improve through this visual narrative if it could be used to communicate to medical professionals her insights and self-reflections about her own body.

One participant took an abstract approach using the outline of the female figure as a starting point (Fig. 172). She asked me if she had to draw inside the lines. I encouraged her to express herself in the way she thinks is best for her. She drew herself inside a box and there are coloured lines coming out of her head that looks like electricity or lightning. She said she wanted to contain it all in a box. She drew a box on a purple lined platform. The box has the same lines exploding out of it as on the head of the female figure (Fig. 173).

The female front figures relate humorous and supportive storylines. One participant revealed her ethnicity as part of her embodiment (Fig. 178). She coloured her skin dark brown and drew her full kinky hair a dark blonde. She said that she likes to bake. She drew an apron and writes a self-help slogan on it: 'keep calm and bake'. I found a book of the same title that says that it will inspire tranquillity and serenity for the home cook.

In Figure 179 the participant transforms the female figure into a superhero with muscle-toned legs and abdomen. The figure looks as though she is leaping upwards. In both figures 178. and 179. the participants are finding and putting forth strength and methods for coping with difficult situations.

Gender-neutral outlines

One of the five total gender-neutral outlines can be viewed in Chapter 2 in the body mapping workshop section. The remaining four are included in the subsequent pages (Figs 180-183). For this exercise I used the definition for gender-neutral as 'suitable for, applicable to, or common to both male and female genders' (Oxford Dictionaries, 2019). This was the least used outline from the human figure outlines.

Figures 181, 182, 183, in the following pages were made by the same participant. This participant indicated an injury on the right groin upper thigh area on figure 182. This was expressed through red Sharpie pen and dripping red shapes. The body is coloured in solid saturated blocks. The participant did not disclose what the colours meant to them. For further iterations of this workshop it would be favourable to have another session that focused on journaling or further exploration of the participants' body maps.

Fig. 180 Gender-neutral 30/7/2018

Fig. 181 Gender-neutral 30/7/2018

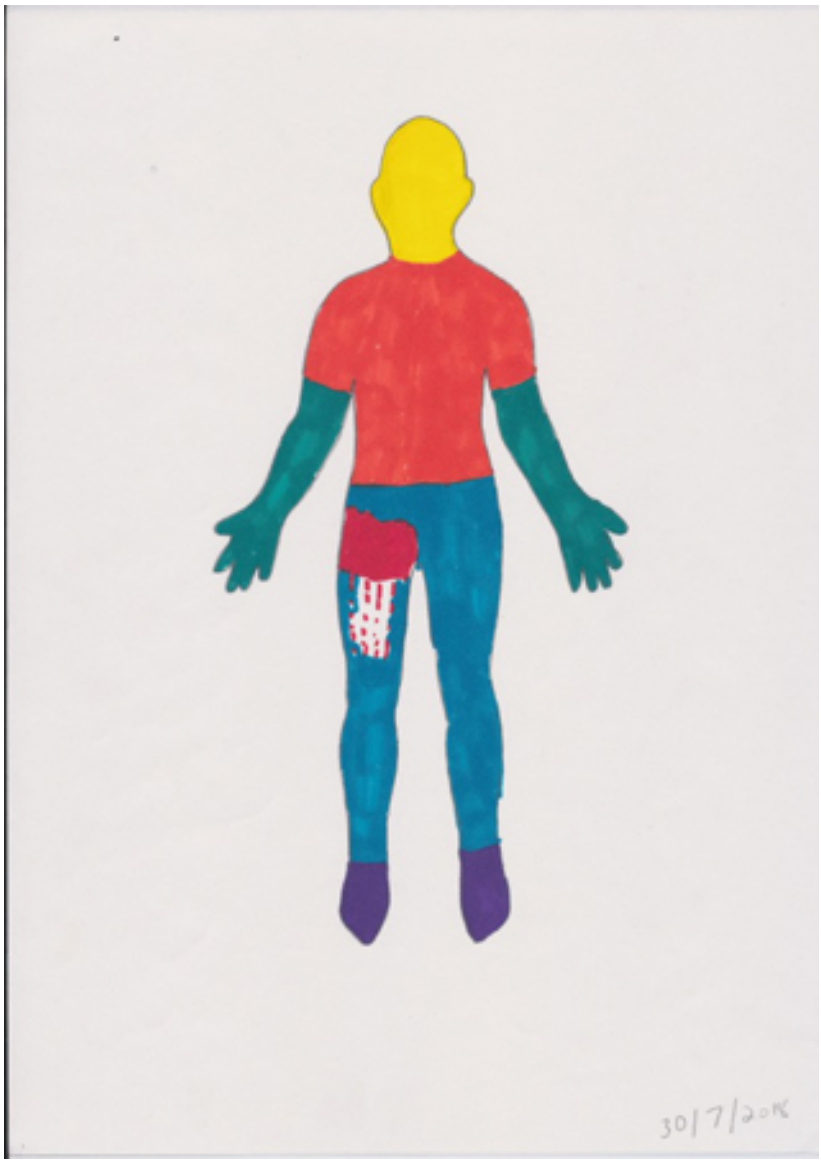


Fig. 182 Gender-neutral 30/7/2018

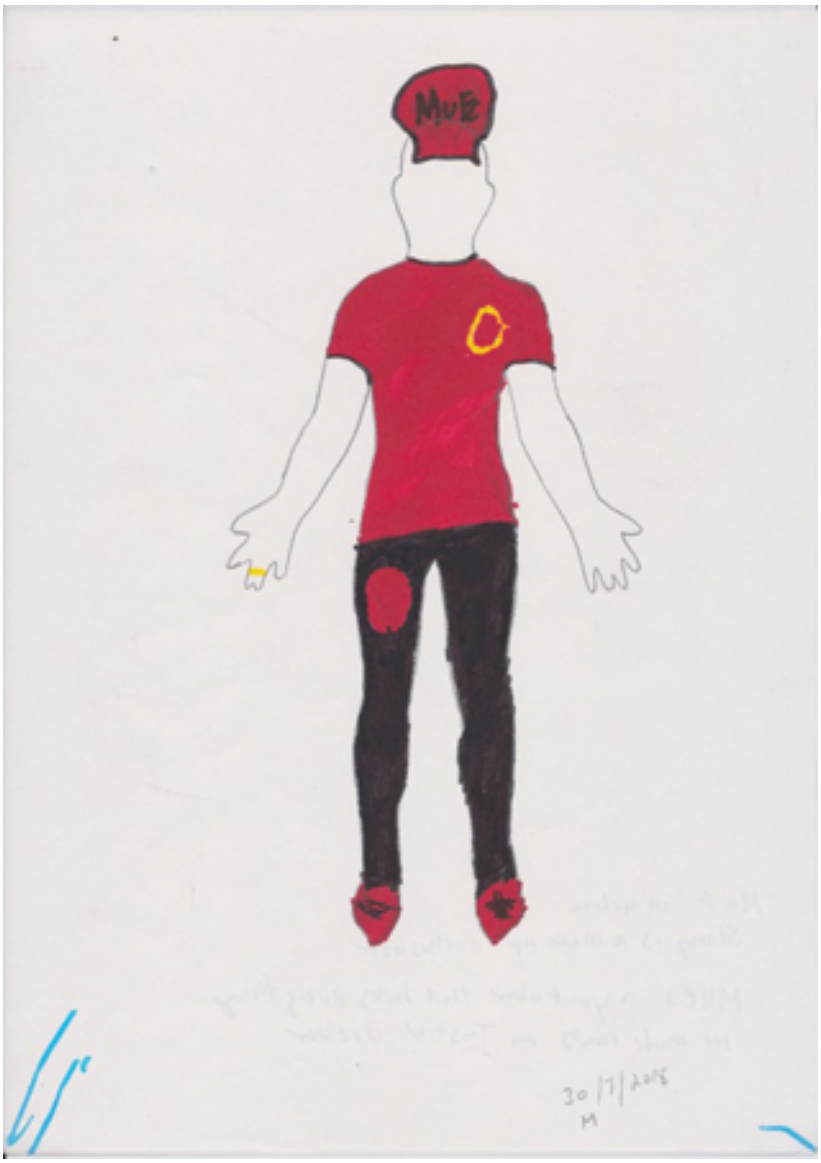


Fig. 183 Gender-neutral 30/7/2018

The body map in figure 183, made by the same participant, now clothes the outline in a red shirt with a yellow circle on the pocket area and black leggings. The arms and face are left without colours. The hands appear to be open and outstretched. The red injury is still visible on the leg. The outline is wearing pointy red slippers with a black design on the top. They drew the word MUE on the upturned bill of a red hat. From a passage from a journal entry from 30/7/2018, I asked the participant what MUE meant and they said that "it is an acronym for makeup enthusiast that is used on Twitter".

This evidences that the participant drew directly from their online life experiences using language from the internet to reference what is happened in their body at the time of

drawing their body map. This indicates the entanglement of digital media platforms with the participants organic bodies and their construction of identity.

The progression of the three body maps being made one after the other indicate a process or stages being kept private and personal by the participant. What the participant does is reveal an injury that appears in the second body map and continues to be present in the third body map.

The other reference to digital media and screen technology is in figure 162. The participant uses a brain outline and draws a tiny smartphone and a TV monitor. She also includes a makeup case and a Ferris wheel in her outline. In figure 153 the participant draws inside of the head front and back outline the inner workings of a turbine with moving gears. On the backside of the head there is an open door and a screwdriver repairing the turbine.

The appearance of more gender-neutral language and imagery is being introduced into mainstream society. For example, 10 countries now permit its citizens to opt for a third gender category X or unknown for passports. In Sweden they have adopted the pronoun 'hen' that allows speakers and writers to refer to a person without including reference to a person's gender. These are steps towards not forcing people to misrepresent their identity which can cause them distress. This is as a result of non-binary and LGBQT representatives of the community asserting equal rights in all areas of life, not only in political policies but also in the everyday world and the virtual world.

Findings

As a result of data produced from patient participation in digital art research activities including digital animations, AAPC and individual and collaborative body mapping, I have found that:

1. Adobe Flash CS4 and Adobe Photoshop CS4 are competent applications to motivate the TYA population to engage with digital art.

    - To evidence Flash CS4, the journal entry for *March 31, 2014* (see Chapter 4 p.82) the excitement and optimism of Participant F. to make animations even though he was not feeling well supports this finding. He actually said, "this is amazing" and he said he wanted to learn something else. He wanted to know if he could download Flash CS4 onto his computer because he was staying in

the wards and wanted to practice on his computer while he was back in the wards.

- To evidence Adobe Photoshop CS4, on p.171, Participant D. explains that he is not good at art. Then when he tried making art on the computer it was easier for him than with traditional art materials. This same scenario occurred with many of the young male participants. It was possible to connect with young people who did not relate to traditional art materials with Adobe Photoshop CS4.

2. Adobe Flash CS4 and Adobe Photoshop CS4 have limitations and constraints when working with participants in the clinical setting at UCLH Macmillan Cancer Centre.

    - The computers that were available to use these programs at this hospital were PC's and they were secured in a permanent station. The participants were limited to using the software at the computer station so they could not use the software at bedside. Both of these programs have a learning curve making literacy not an immediate process. The participant must be instructed on how to be able to use them for the research activities, with the exception of those that are already literate in these programs. A participant could spend as much time learning how to work the program as doing the research activity. Some participants learn faster than others, this limited the expectations of what could be produced within the available time constraints. There was not a printer available at the hospital to print out research activities for the participants to keep at the time of completion. Only participants that had access to e-mail and a home computer or smart phone could have their activities forwarded to them.

3. The experience of learning how animation functions and working closely with a timeline promotes health and wellbeing.

- Depositing keyframes in the timeline can offer an opportunity for structure through repetition. An affordance of repetition is that it can have a grounding and calming effect on the participants and help to relieve symptoms of anxiety.
- The participant is able to watch a repeating video loop of what they have created. This has a meditative quality (See fig-7 black ball p.74) and reinforces a sense of accomplishment in the participants.
- The participants are supported and guided in learning and in the development of skills, confidence and self-esteem.
- The participants display a sense of achievement when seeing what they can make move.

4. Crafting digital objects from images culled from the internet to be used in digital canvases contributes to a process of self-reflection in TYA participants. Self-reflection can lead to:

    - Improved understanding of oneself, and an ability to reflect on different aspects of one's life.
    - Empowerment through taking control of one's health, feeling that they can actually control what is damaging their health.
    - Enhanced empathy that leads to understanding the diversity of the human experience.

5. Body mapping is an effective method for data collection with individual TYA cancer patients.

    - Individual TYA's respond to the body mapping format on A4 paper used in this study because of its achievability. Within a short space of time the patient is able to express a visual narrative about their body.
    - This activity is not dependent on having artistic expertise, only a willingness to participate.

6. Lifesize body mapping with collaged printed media is an effective data collection method with individual TYA participants.

    - Individual TYA's respond positively to using collaged imagery on a life-sized body map because it provides more space to freely move and place the cut-out media.
    - The images can be juxtaposed and re-juxtaposed leading to found meaning making and self-reflection (see Fig. 34 Body map collage 2. p.112).

7. Life-size collective body mapping with collaged printed media is effective with multiple TYA participants.

    - The TYA's respond well to the concept of collaboration. This activity promotes self-organization amongst participants.
    - Relevant themes that apply to their shared experiences of cancer emerge.
    - Multiple voices can be represented in a single body map (see Fig. 35 Group body map p.115)

8. A digital body mapping prototype that can promote health and wellbeing can be built based on the findings from this research data.

    - In Chapter 4. p.63 I create a digital prototype sketch and digital prototype sketch tools Chapter 5. p.118. The sketch and tools can be used as a guide to inform developers of how to build the next iteration of a working prototype that could be piloted with the TYA's for user testing.

9. Participation in digital art research activities promotes health and wellbeing in terms of the 'achieving' and 'being active' indictors of the GIRFEC framework (Scottish Government, 2018).

    - Through engagement with the digital art-based research activities, the TYA's are being active see Chapter 4. Fig. 25. P.100.
    - The activities were designed to allow the participant to achieve through participation. Participation in the process equals achievement. For example, the

completed body maps in the ‘Drawing body maps section’ in Chapter 4 p.101 and Fig. 26 Hands body map p.100.

10. Participation in digital art research activities promotes health and wellbeing within the What Works Center for Wellbeing Network’s consensus three dimensions of wellbeing (2018). These indicators are increased optimism, capability, and creative skills and expression.

    - In Chapter 4. In journal entry March 31, 2014 p.82 the participant F. exhibits increased optimism throughout the workshop session.
    - In Chapter 4. In the ‘digital workshops’ section p.71 the activities illustrate how capability and creative skills can be increased through workshop participation. For example, journal entry March 31, 2014 p.84 participant F wanted to go on learning more after he achieved some literacy.
    - In journal entry May 18, 2017 p.112 the participant develops her self-expression through moving and juxtaposing cut out media to paste onto the life size body map. This participant related easily to the print images and was able to use them to talk about herself.

This data is important because it contains self-reflections of the lived experiences of the participants in the clinical environment and beyond. The participants were empowered to create their own self-reflexive data that informed the next iterations of the research activities. The patients’ participation is visible in the iterative process that evolved into the digital body mapping prototype. The level of interest that the participants showed in working with digital collaged imagery translated into the prototype life-sized body map with collaged printed media and the life-size collective body map. The immediacy that the digital object offers and the context of the digital within the lives of the TYA’s led me to merge the processes of AAPC, body mapping and collaged body mapping with the digital prototyping. By assessing what is achievable for the participant the findings can be applied to software design to programme bespoke art therapeutic activities.

Chapter 8: Conclusion

> 'We search for ways to see ourselves. The computer is the new mirror, the first psychological machine. Beyond its nature as an analytical engine lies its second nature as an evocative object' (Turkle, 2005 p.21).

As a digital artist and researcher, I have been curious about the therapeutic benefits of digital art media from the start of my experience teaching young people digital animation and digital arts in 2006. While teaching digital arts and animation I recognised that health and wellbeing were connected to the process of learning about and making digital art with young people. I surmised that there were therapeutic benefits from engagement with digital arts.

There is much to be said about the negative effects of an array of digital media and the dangers of its misuse by young people; for example, internet gaming disorder (IGD) (Carr, 2011; Stiegler 2010; Greenfield 2009). There are those who hold the view that digital media is not therapeutic (Choe, 2014; Choe, 2017; Williams et al., 1997; Asawa, 2009). Art therapists in Choe's study felt that the absence of messiness, tactility, texture and smell in art-making applications is a disadvantage (2014). While accepting the aforementioned research, I maintained my perspective and continued in pursuit of my research question; what are the precise health and wellbeing benefits of using digital arts-based research methods with teenage and young adult cancer patients?

I am not alone in my supposition, for example in 1985, DJ Weinberg discussed the potential of computer art therapy as an adjunct to conventional rehabilitative art therapy with quadriplegic, cerebral vascular accident (stroke), and brain trauma patients (Weinberg, 1985). In 1987, Canter evaluated the effects of the combination of Apple Macintosh computers and creativity software in art therapy sessions (Canter, 1987). There are therapists who have written about the therapeutic value of digital media (Alder et al., 2011; Barbee, 2002; Hartwich & Brandecker, 1997; Horovitz, 1999; Malchiodi & Johnson, 2013; Martin, 1997; McLeod, 1999; Orr, 2005; Parker-Bell, 1999; Patterson, 2010; Rutherford, 2002; Seiden, 2001; Thong, 2007; Wolf, 2007).

However, in the recent reviews of the impact of the arts and art therapy on health and wellbeing there has been little in the way of research that engages with digital visual arts. Art therapist Rick Garner found that 'One thing is certain, what became extremely obvious during the research for this book (editor of *Digital art therapy*) was the dearth of art

therapy research publications regarding technology use' (Garner, 2017, p. 15). This research aims to occupy this gap in the literature and provide insights into how arts-based research methods with digital visual art can provide evidence of the link between wellbeing and participating in digital visual arts.

I was awarded NHS R&D approval to do this work in the teenage ambulatory cancer unit at University College Hospital London. Over a period of two years and nine months I worked with an estimated total of 120 anonymous participants in outpatient ambulatory care at MacMillan Cancer Centre UCLH.

With the evidence collected from this research I sought to build a speculative art therapeutic prototype, based on my examination of the visual art data made by the TYA's. At the start of this research and development process I did not know what this prototype would look like, what it would do and for what reasons. By spending time with the TYAs, the design process revealed itself. The research evolved from my immersion within the clinical environment and with the TYAs' generous participation.

I designed the research activities using an iterative multi-method approach to perform co-design through participation and collaboration with and for the TYA patients, narrative analysis to examine journal entries that focused on the workshop experience, digital visual ethnography for the collection of digital images and video stills and body mapping - a visual story telling method which uses drawing within a workshop structure (Chapter 2). The aim of the workshops was to observe the TYA participants in the process of creating digital art and traditional artworks based on my research design activities. The activities ranged from learning to bounce a ball in flash animation, exploration of digital self-portraiture through collage and abstraction and the use of traditional art media to make body maps. The digital artworks and body maps produced by the TYAs serve as visual data to accompany observational journaling for analysis.

Through the experiences of working closely with the TYAs for several years, it was possible for me to conceptualise the prototype, which is a design for a digital body mapping application based on merging the AAPC, collage body map and the traditional body map data. The prototype uses an archive of digital image symbols to aid the participant in creating a visual narrative of their own body.

In the hospital environment it is the medical professionals that define the patient's health condition through medical imaging and terminology. The body mapping

prototype empowers the TYA patient to articulate from their own perspective what is happening in and to their body through images.

Notwithstanding the ubiquitous nature of digital art technology, art therapists today face challenging issues surrounding the use of digital art media and are reluctant to adopt it within their practice. Digital literacy, difficulties manoeuvring hardware and software, cost and emotional reactions to the digital medium are cited as some of the obstacles they have encountered (Choe, 2014; 2017; Williams et al., 1997; Asawa, 2009). Art therapists are beginning to embrace digital art technology, though not without some growing pains. For example, Wood states in her report of digital technology that 'Everyone I interviewed felt their art therapy training did not equip them to work confidently with digital technology' (Wood, 2015 p.22).

Art therapists, artists and arts in health workers who do embrace digital art technology and have been researching its health and wellbeing benefits, constitute the emerging field of digital art therapy (Malchilodi, 2018; Garner, 2017). However, as Garner observes, DAT is still in its infancy (Garner, 2017, p. 15). Even though there has been research with computers for art therapeutic purposes for more than 16 years, the quantity of art therapy research dedicated to the topic of digital media remains small compared to the archives dedicated to traditional art media. DAT scholars and practitioners recognise the need for and are now seeking to expand the growing body of research with evidence-based DAT interventions. It is within this dynamic field of DAT that I situate my research and make my contribution through my research and development of a digital body mapping prototype built upon my findings from using digital arts-based research methods.

Limitations

Time

The research for this prototype was limited to working with TYA cancer patients in ambulatory care. A minor percentage of carers of the patients who were attending the clinic participated in the research. Patients can wait up to three hours before beginning a medical procedure. It is within this space of time that I could recruit participants. There was also the possibility to work at bedside while the participant was having chemotherapy if they chose to.

The research only included participants who were recruited in the hospital environment. Because it was ambulatory care, I did not often have the opportunity to work

with the same participants weekly. The workshops were limited to a one-time session for individual participants. It was not possible to do routine repeat exercises with individual participants.

Equipment

There were eight computers available to use for this project that had flat keyboards that could be disinfected easily. The participants complained that the keys on the keyboard were difficult to press. There were three detachable keyboards for use and some computer mice. I was able to negotiate with the hospital to buy four more mice to use.

Initially I used free software that expired within 40 days for the workshops. Once the software expired the play specialist agreed to buy the software that would equip four computers. The workshop activities were designed to work with the software that was made available by the hospital, which was Photoshop CS4 and Adobe Flash CS4.

The participants would have benefited from the use of tablets at bedside, though the hospital did not have them available at the time of this research.

Data collection

Working with patients identified as anonymous participants removed details such as age and gender resulting in less data about individuals. For additional information like age, ethnicity or gender I needed to rely on my observational journaling for comparative analysis. Frequently participants did not save their data or were not happy with what they had made and deleted it. This study uses qualitative research methods only.

Application

This study is limited to the research and design for the digital prototype sketch tools only. I was unable to produce an application based on my digital arts-based research methods and prototype. I was awarded funding from graduate school fund at Goldsmiths in 2017 for building the prototype with computing undergrads, though I went on maternity leave and forfeited the funding (See appendix p.). Therefore, there is no method to quantify user experience until a future application is piloted with TYAs.

Findings

Out of the 120 participants 28 chose not to share their data for the purposes of this study. As a result of patient participation in the digital art research activities including digital animations, AAPC, individual and collaborative body mapping, and the data that they produced I found some precise health and wellbeing benefits. I found that the TYAs were able to exhibit indicators of wellbeing in correspondence with GIRFEC (Scottish Government, 2018) and the first three dimensions of wellbeing in What Works for Wellbeing and Sport (Daykin et al., 2016). I arrived at these findings through comparing the digital images and video stills with the corresponding journal entries. I searched for themes and evidence that qualified as health and wellbeing indicators described.

- Achieving: being supported and guided in learning and in the development of skills, confidence and self-esteem in the clinical environment and in the community.

- Active: having opportunities to take part in activities such as play and recreation which contribute to healthy growth and development.

- Included: having helped to overcome social, educational, physical and economic inequalities, and being accepted as part of the community in which they live and learn (i.e. the Teenage Cancer Trust community and the clinical environment).

- Increased optimism

- Self-Reflection

- Creative skills and expression

- Personal identity

This research evidenced that body mapping is an effective data collecting method with TYAs. Using an iterative approach, I furthered the original concept of the body map by providing printed media to be used for the participants on one life-sized shared body map. When using the extended collaborative collaged body mapping method, the TYAs exhibited qualities of the social dimension in What Works for Wellbeing and Sport, which includes

belonging and identity, sociability and new connections, bonding and social capital, reducing social inequalities and reciprocity

The digital art data produced by the TYAs impacted the design of the prototype in several ways. For example, the AAPC data provided evidence that collage would be an effective strategy to use for body mapping. The TYAs' participation in digital media activities led to experimental methods with traditional art media such as the body map. The traditional art media data served to develop further digital iterations of the prototype.

These methods could not have arisen without the TYAs' willingness to be observed while creating artworks within the co-design workshop structure. The main features of this structure are participation and collaboration while designing with, and not only for, participants. I observed that the TYAs could continue to work individually on their artworks, though I found that when they had the opportunity to interact, it brought about qualities of the social dimensions of wellbeing. This prompted me to extend the body mapping method through collage material and invite up to six participants to collaborate on a unified body map.

This collaborative version gave the TYAs the opportunity to share a collective voice, identity and aesthetic. The group process became participant-led. The participants conferred with one another rather than with me about what steps to take next. The TYAs formed a self-organising unit to produce a shared vision of their embodied experience. Had I not worked directly with participants the iterative developments mentioned here could not have occurred. It is through patient participant that the research could progress in innovative directions.

Artists can bring a wealth of knowledge of their discipline to the design of bespoke research activities that produce data which, in turn, inform the prototypes for software development. Artists can also design and make prototypes with the applications that they have a mastery of. The impact of bespoke collaborative research methods and prototyping based on an artist's discipline can be extended further when working with different disciplines.

In the example of this research I worked with a variety of healthcare providers and had the benefit of the observational study of the TYAs within the clinical environment. Rich data can be generated and collected from the research design created by artists in conjunction with professionals in relevant disciplines to their study group. Shona et al.

(2015) state: that more needs to be done on this front. Suggestions for ways to move forward include:

- Art therapy researchers working more closely with researchers from 'purely' arts disciplines (e.g. literature, art history, fine art) in order to establish what effect arts engagement might have (Shona et al., 2015).

The assertions of Shona et al. can be applied to the involvement of digital arts practitioners with art therapy professionals.

Practical applications/implications

The practical applications for a digital body map prototype when produced as software is that it could be used on a tablet or a smartphone, the implication being that it may be used as a communication aid for patients to use in medical consultations. The digital body map can assist a patient to tell a story visually of what is happening in their body. This is an activity that can be done in addition to a consultation or medical procedure, having done this before and after, these two body maps can be compared for analysis.

The digital body map potentially gives the patient the opportunity to create a self-reflexive visual narrative that has the ability to convey their physical state to others that may need to understand their condition. The digital body map application could also be used by medical professionals to visually explain medical procedures. For example, if a patient is going to have a bone marrow transplant the consultant could use the prototype to visually demonstrate what happens during the procedure and use images to indicate what it may look like and feel like.

The results of this study have implications for positive social change at the individual level for patients, at the organisational level for hospitals and at the societal level.

Individual level

At the individual level, the results of this study may inform TYA patients about the health and wellbeing benefits of engaging with digital arts. This could happen through direct experience of participating in research workshops or through a published article. The results

could motivate TYAs to integrate digital arts activities into a wellness routine as an adjuvant to cancer treatment.

The patient can use the speculative digital body map prototype to share important information about their physical condition with medical professionals. The consultant can use the patient's body map to formulate questions to find out more about a patient's health.

The results from this study have the potential to generate further art-based research in DAT therefore expanding its evidence base. The results from this study contribute to the small and growing body of DAT research.

Organisational level

At the organisational level, within the MacMillan Cancer Centre UCLH there are implications for this research to increase the visibility of and accessibility to DAT. The benefits of this research could incentivise the hospital to make DAT available to TYA patients in the ambulatory care centre. This could be done through the NHS APPS Library, where there are digital tools to help manage and improve health. To date, the library has categories for learning disabilities, mental health, cancer, diabetes and more. There is a vacancy in the library for DAT applications.

Digital arts-based research has the scope to integrate with UCLH culture to promote health and wellbeing within the TYA population. As the field of DAT expands there is the potential to make digital art-based research projects available on prescription at UCLH. This research may be instrumental in promoting personal agency within the TYA population to mobilise their self-care plans for recuperating from cancer. This can start with TYAs seeking to engage with DAT for additional support in cancer recovery.

Societal level

The results of this study might have implications at the societal level. This research is an investment in the wellbeing of society. The heart of this project resides within the care and attention given to the wellbeing of TYA cancer patients. Society needs innovative ways to support TYAs through the most difficult of times. Using digital art and traditional art media can respond to this need. Young people deserve to have access to DAT if and when they need it for the maintenance of their health and wellbeing and for medical issues. Most of all, young people have the right to be understood as well as possible.

Society as a whole can benefit when its young people are noticed and given assistance when they are struggling with life-changing health issues. This research could signpost TYAs to find resources to assist them with adopting DAT into their lifestyle. The more that TYAs adapt to a culture of self-care through the use of approaches like digital arts-based research activities, the more society will strengthen. It will be fortified through upcoming generations of strong, resourceful and resilient adults equipped to raise future generations.

The use of body mapping to visually narrate a patient's story about their body in a medicalised setting has the potential to alter the way that medical professionals and patients communicate with one another. This speculative prototype proposes an alternative way to present autobiographical data in the hospital setting through visual imagery. The impact of improved communication within the medical environment is potentially a positive development for healthcare throughout society.

It is possible that digital arts-based research could influence interested artists and arts in health workers to add to the expanding body of knowledge about the use of digital arts media for therapeutic and health and wellbeing outcomes. The more opportunities for people to use digital arts for wellbeing the more likely it is that the overall sense of wellness amongst society can be uplifted.

Recommendations for further study

Piloting an application

The main area for future study is to produce a digital body mapping visual autobiographical storytelling application using the research and design of this prototype, then to follow up with TYAs and pilot the application at the MacMillan Cancer Centre in the ambulatory care centre. Using tablets for this research would be optimal.

This iteration of the research would provide the opportunity to collect much needed quantifiable data to contribute to the field of digital art therapy. Potentially, the participant's completed body maps could be presented to the consultant during her medical assessment as a way to visually communicate more in depth about her condition. This is an area to be examined further to assess this possible benefit of the application.

Shona et al. back up my strategy with their recommendations for future studies in their review of art therapy research, suggesting that the way forward includes:

- Arts therapy researchers conducting follow-up studies as routine practice in order to establish the longer-term effect of arts interventions (Shona et al., 2015).

The piloting of the digital body mapping application would allow for the following unanswered research questions to be explored for further research:

- How does digital software/devices designed by artists differ from the mainstream?
- In what ways can practice-based research in the digital arts contribute to more effective relationships between art therapists, technology, hospital management, healthcare workers and patients?

Collaborative body map

The collaborative collage body map method that I developed in the co-design workshops was a finding that I did not anticipate. I observed that this research activity promoted inclusivity and led to a unique visual expression of the group's self-organisational process. This method has the potential to collect data from multiple individuals simultaneously. This could be an advantage when looking to collect numerous viewpoints about a specific research question that needs to be quantified.

There is scope for further iterative research projects using this method with TYAs. Continued activities with collaborative body mapping methods could lead to the development of an interactive digital prototype. For example, using touch screen technology participants could simultaneously work on a large-scale body map on a suitably sized screen. Innovations such as gesture recognition could be experimented with. Innovations like these might make it possible for individuals with limited mobility to participate. This area of research may uncover new ways to promote inclusivity among participants in the research activities.

B*ody mapping method for quantitative data collection*

Although body mapping is a qualitative research method, it could be used to collect quantitative data as well. Further research could be performed to design bespoke body map features that could collect specific quantitative medical data.

For example, the body map could be used to quantify where pain originates and to measure levels of intensity in a patient after having a particular medical procedure. This

method can then be used to produce a digital prototype. The same treatment could be applied to the collective body map therefore opening up the possibility to collect multiple individuals' data simultaneously.

Digital arts-based research in a new context

A replication of this study could be foreseeable with adult cancer patients in ambulatory care. This would serve to provide data for a future comparative examination with the original study with TYA cancer patients. This could only be possible after spending time in the clinical environment with adult patients.

The research activities may be designed differently because of adults' technological needs and responses to digital art media. These and other variants should be taken into account when designing research activities, prototypes and possible computer applications that seek to reflect the aims of the original digital arts-based research project.

***Digital arts-based research* in the global community**

There is opportunity for digital arts-based research beyond new contexts in the clinical setting and working with a study group that has a specific medical condition. Digital art therapy can be used as a method to maintain wellness and also as a preventative health measure in healthy people.

The general public can benefit from art-based research to examine how best to develop accessible art therapeutic software for everyday use. There is an array of mental health applications available for mental health conditions such as anxiety, panic attacks and suicidal tendencies.

Within this area of research, new ways to introduce DAT to the public could be examined. Providing the general public with DAT options that they can turn to in difficult times or to give them support in their personal wellbeing plan is a way forward for the maintenance of a healthy and robust population.

Collaborate with art therapists

For future iterations of digital arts-based research methods, in-depth therapeutic perspectives could be gained through a collaboration with an art therapist. Shona et al. call for arts therapy researchers to engage in more collaborative work across geographical areas and with researchers at other institutions as well as with researchers in purely arts

disciplines (2015). The professional experience that the art therapist can bring to a project such as digital arts-based research methods, would profoundly enrich the research and design process.

A co-design research method has the potential to add to the knowledge base of both the digital art researcher and the art therapist. This would provide the setting for an equitable knowledge exchange between artist and therapist. Shona et al. assert that greater collaboration would result in larger sample sizes and more reliable results (2015).

In conclusion, this study has revealed that the fascinating field of digital art therapy and healthcare is expanding. For this to continue, further research is required from art therapists, artists, arts in health workers, medical professionals and technology experts to produce a robust evidence base that is essential for growth. This thesis aspires to extend an open invitation to these researchers to explore, document and share their findings. It is my ambition to contribute this research to the evolving community that aims to spread wellbeing through inventive digital art therapeutic initiatives.

Appendix - 1

Workshop poster

Goldsmiths
UNIVERSITY OF LONDON

University College London Hospitals NHS
NHS Foundation Trust

Artist Designed Art Therapeutic Software
Research Project

You are invited to take place in a research project that is investigating
the health and well-being benefits of participating in digital animation and digital art activities. This leaflet explains why the research is being carried out and what will be involved if you choose to take part. Please feel free to ask the researcher if there is anything that is not clear or you would like more information.

What is the purpose of the study?

The purpose of this study is to assess the potential value of participating in digital animation and digital arts as an enrichment activity in hospitals and health care settings. There is current research that indicates that participation in the arts increases confidence, sense of belonging, and can act as an adjuvant to cancer treatments. It is the aim of this research to explore the potential advantages of the

digital medium for art making in the hospital and health care setting.

Do I have to take part?

It is entirely up to you to decide whether to take part or not. If you do decide to take part you will be given this information leaflet to keep and be asked to sign a consent form. Even after you have decided to take part, you are free to withdraw at any time without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of the care you receive.

How long will the session take?

Session lengths vary depending on how long you would like to participate in the digital animation and digital art workshops. Usually sessions last between 30-45 minutes. You can choose to end the session at any point.

What will happen if I take part?

If you agree to take part, a researcher will explain more about the handling session and any answer questions you might have. The researcher will ask you for permission to keep any artwork that you make in the workshops for the purpose of visual data. The researcher will also ask you to indicate how you are feeling using a series of short questions. You will be asked to sign a consent form.

After the session you will be asked again to indicate how you are feeling. If you have any further questions, comments or observations you will be welcome to discuss these with the researcher.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks involved with taking part in the study. You are not liable for any breakages to the computers that might occur during the session.

Goldsmiths
UNIVERSITY OF LONDON

University College London Hospitals NHS
NHS Foundation Trust

Will my taking part in this study be kept confidential?

Yes, only members of the research team will have access to your personal details. This could include access to sections of medical notes and demographic data. All information collected during the course of the research will be treated in the strictest confidence. Data may be stored by the custodians, University College London Hospitals and Goldsmiths University of London for future studies.

Data may be transferred with no personal identifiers to researchers or sponsors of the research (including countries outside the European Union) that may not have equivalent data protection legislation. All efforts will be made to ensure the security of this information.

The results of this study may be published or used for teaching purposes, however, your name or other identifier will not be used in a publication or in teaching material unless your specific permission has been sought.

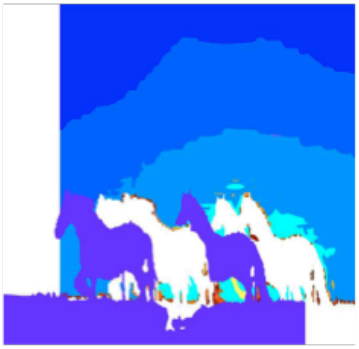
For more information please contact:

Rebecca Miller
Mphil-PhD Candidate
Art and Computational Technology
Goldsmiths University of London
9 Sedgemere Ave. N20SY
London, UK.

tel: 07551968529
email: co901rm@gold.ac.uk

Artist Designed Art Therapeutic Software
Research Project

Patient Information Leaflet



University College London Hospitals NHS
NHS Foundation Trust

Joint Research Office

Office Location:
1st Floor Maple House
149 Tottenham Court Road
London W1T 7DN

Postal Address:
UCL,
Gower Street
London WC1E 6BT

Tel: 020 3447 2177/79833 Fax: 020 3447 9937
Websites: www.uclh.nhs.uk; www.ucl.ac.uk; www.ucl.ac.uk/jro

FINAL R&D APPROVAL – NHS PERMISSION

11/02/2015

Dear Mrs Rebecca Miller,

Project ID: 14/0515 (Please quote in all correspondence)
REC Ref: N/A
UKCRN ID: N/A
Title: Research and Development for Artist Designed Art Therapeutic Software

Thank you for registering the above study with the Joint Research Office (UCLH site). I am pleased to inform you that your study now has local R&D approval (NHS permission) to proceed and recruit participants at University College London Hospitals NHS Foundation Trust, subject to the Sponsor's written 'green light' confirmation.

Please note that all documents received have been reviewed and this approval is granted on the basis of the key documents provided which have obtained a 'notice of favourable opinion' by the Research Ethics Committee (REC):

Document	Date
REC notice of favourable opinion and REC approved documents	12/11/2014
MHRA notice of acceptance letter(if applicable)	(n/a)
Agreement between sponsor and UCLH (if applicable)	(n/a)
ARSAC licence (if applicable)	(n/a)

As Principal Investigator you are required to ensure that your study is conducted in accordance with the requirements on the attached sheet. These include the conditions of your NHS permission.

Please note a summary of the study will be obtained from IRAS A6-1 for the **UCLH Research Gateway** which is available to the public at http://www.uclh.nhs.uk/Research/Pages/researchdatabase.aspx.

Do not hesitate to contact a member of the team should you have any queries.

Yours sincerely,

G. Muzaker

PP: Professor Bryan Williams
UCLH Research Director

NHS R&D approval letter

Appendix - 2

Interview with Guy Noble, curator of NHS trust hospitals

1. As arts curator at UCLH, do you think there is a role for art in the digital environment that patients access daily at the hospital through smartphones, computers and tablets while visiting and staying as well as services that extend into everyday life?

1) Absolutely there is a role. I see my role as extending access to the arts in the broadest sense and if that is digital then certainly. I think we are almost at the tipping point for digital art as the technology advances and the medium to display digital art improves (screens prices reduce, weight and heat outputs, robustness) more public institutions will be more confident in investing in this area. Also with the emergence of social media, Pinterest, Instagram etc, people are becoming curators of their 'lives'. As a result I think people are already sophisticated readers of the digital world and it comes down to those that are working in the public realm to realise a mechanism in which to allow patients to personalise their spaces through digital means, be that through providing choice of lighting, or content on screens.

2. As the future of digital healthcare is extending into virtual environments and services to be provided by virtual nurse avatars, how would you see yourself as the arts curator of the virtual hospital?

2) I've not really considered this - other than there is a need to develop a digital collection of art works that can be offered to patients whilst waiting. There is certainly work to be done to develop apps or equivalent and offer this to patients at the same point of contact they are offered nurse avatars etc.

3. In your book *Museums, Health and Well-Being*, you assert that 'museums provide engaging environments that contribute to a positive state of psychological and physiological health'. In your study you bring traditional museum objects to patients and evaluate whether interacting with them brings about health and well-being outcomes. Contemporary museums today contain an array of digital and virtual art forms on exhibition. Do you think that digital and virtual art works can have the same positive health and wellbeing effects on patients as the museum objects you made available to the patients in your study? If so, as a

curator how can you make digital and virtual art available for the benefit of hospital patients? What would this look like?

3) This is potentially a rich area of study and I guess it would depend on what the interaction looked like. Both in terms of how the patient interacts with the art work (does it demand active engagement to work?) and how such a session would be facilitated. I certainly don't see any reason why digital and virtual artforms should not benefit patients' wellbeing, and certainly the aural experience would need to be considered too. I would be interested in trying to develop something on this vain if you are interested.

I'm currently working with Cinimod Studios and the artist Dominic Harris to bring digital art into the PBT and phase 4. The work will be interactive whereby patients will have the opportunity to interact with the art and as mentioned earlier control and curate their own environment. Happy to show you initial ideas.

4. There is anxiety and questions concerning ethics that surround the role of digital healthcare and the concept of robotic healthcare, that the digital and virtual will replace human workers and care. Are there the same feelings that surround digital/virtual art and the replacement of traditional analogue art in the hospital environment?

4) No – not that I'm aware. As discussed above I think it's important to provide a range of artforms for which patients can interact. I don't think it's a question of either/or. Art in the realm of the digital is important as it can encourage us to question and interrogate these concerns.

5. Is there a way for digital/virtual art to occupy the same hospital environment and to support and complement one another?

5) Yes – in a number of ways. Technology offers us a way to engage with art in new ways, be it through bringing additional knowledge through audio guides or through digital drawings in response to a traditional painting. The virtual world offers us a platform to interrogate the landscapes in which art was created too. Imagine walking through the artist's studio, or the garden in which the painting was created. For patients who are immobile or long-term residents the virtual or digital brings the outside in.

Subject: Last Tuesday

From: annika.davidson@uclh.nhs.uk

Date: Fri, September 20, 2013 12:58 am

To: rebecca@blackbirdspace.com

Dear Rebecca

I have been trying to call you, but not been able to reach you, so I thought I would email instead. I'm sorry I didn't get to catch up with you properly before you left last Tuesday. Perhaps we can have a chat before you start next week.
I just want you to know that I really appreciate your work and time you spend here. I'm still confident that it is a worthwhile project and want to support you to get an increase in users. You have a very pleasant and sensitive and respectful attitude towards the patients.
I am wondering if you would like to try the Wedneday 25/9 next week, as Francis is not in next week? Say between 11- 1pm? But if you want to keep it to the Tuesday that's fine too, I just thought I would give you the option.

Hope you have a lovely weekend

BW

Annika

This email is confidential and is intended solely for the person or entity to whom it is addressed. If this is not you, please forward the message to mail.administrator@uclh.nhs.uk. We have scanned this email before sending it, but cannot guarantee that malicious software is absent and we shall carry no liability in this regard.

We advise that information intended to be kept confidential should not be sent by email. We also advise that health concerns should be discussed with a medical professional in person or by telephone. NHS 111 can also provide advice. We shall not be liable for any failure to follow this advice. University College London Hospitals NHS Foundation Trust (UCLH)

Appendix – 3

UCLH Workshops research log

2013 17 male 3 female animation 20 total participants

February - 10:45 - 12:30 pm

Tuesday, February 19, 2013.

- I loaded a free 30-day trial onto 3 of the six PCs in the hub
- 1 male animation participant

Importance: I started my research after a long induction process in the hospital. I can now see how my ideas function in practice. See journal entry.

Tuesday, February 26, 2013.

- Today I did not hold a workshop because it was the official opening of the Teenage Cancer Trust Hub in UCLH Macmillan Cancer Centre. Arsenal Football Club raised the funds towards building the facility.

Importance: The area in which I lead the animation workshops that include the computer gaming space and education zone was donated by Arsenal football club. My digital animation workshop was the first of its kind in the UCLH Macmillan Cancer Centre London.

March - 1 - 3pm

Tuesday, March 5, 2013.

- I approached patients at bedside and in the Hub and talked to them about my workshops. They were more interested in doing the arts and crafts on offer at the art table.

Importance: It is difficult to recruit participants. I am still learning about the ambulatory care environment and the different procedures that the patients go through.

Tuesday, March 12, 2013.

- I worked with 1 male animation participant and was unable to save any data. The participant wanted to delete the artwork.

Importance: When the participant does not want to save the artwork or give me permission to use it, delete it from the computer and empty the trash.

Tuesday, March 19, 2013.
I did not go into the hospital today.

Tuesday, March 26, 2013.

- I negotiate with Annika to buy Flash Animation CS4 for the computers.

  Importance: It was important for me to ask for what I needed to continue on with the animation workshops.

April - 1-3pm
Tuesday, April 2, 2013.

- Annika agrees to buy Flash Animation Pro CS6

  Importance: The play specialist and youth support coordinator Annika believes that the animation workshops are worthwhile and agrees that they should continue.

Monday, April 9, 2013. - 1 participant

- I worked 1 female participant doing drawings at bedside. Although we were unable to do animations on the computer, I was able to ask her about her use of digital technology.

  Importance: The participant indicated that she likes doing activities on the computer like Facebook and texting on her phone.

Monday, April 22, 2013.

- The software has arrived though I need to give the IT specialist my teaching ID to load onto computers

Importance: The process of having the software and hardware to do digital art with the patients is not straightforward. To do this project I need access to hospital specialists to enable the software on the computers.

Tuesday, April 23, 2013.

- Working on literature review to be handed in at the end of the week.

Importance: The literature in my thesis reflects some of the same problems that art therapists have with using digital art technology with clients. In my case needing to rely on the IT specialist to download the software on the computers.

May - 1-3pm

Tuesday, May 7, 2013.

- Richard UCLH IT specialist gives the computer password to Annika so the software can be downloaded onto the computer.
- I have a bad cough and cannot come into the hospital.
- Two serial numbers are needed to load the software.

Importance: It takes time and patience to setup a digital animation research project when there is not a precedent for digital art in the hospital.

Tuesday, May 14, 2013.

- I am waiting for the software to be installed to resume the workshops.

Tuesday, May 28, 2013.

- Still waiting to re-start workshops.

Importance: I did not foresee that it would be so challenging to work with digital art in the hospital setting.

June - 1-3pm

Wednesday, June 5, 2013.

- I obtained the second serial number to load the software on the hospital computers.

  Importance: When working within an institution it can take longer than expected to achieve tasks.

Wednesday, June 12, 2013.

- I designed a promotional poster for the animation workshop.

  Importance: I thought about the kind of imagery that would appeal to the TYAs. I settled on some images from graphic novels of teenagers and young adults with a complementary font for the text.

Wednesday, June 19, 2013.

- The software is now loaded on two of the eight computers.

  Importance: Now that I know how the process of working with the IT specialist works at UCLH I will be better equipped to install Photoshop on the other two computers.

Wednesday, June 25, 2013.

- I worked with Flash Animation to prepare myself to work with the participants.

  Importance: The computers need new mice to work with. The external keyboards are easier to work with than the flat stainless-steel keyboards that are used for hygiene reasons to be able to wipe off with antibacterial wipes.

July - 1-3pm

Tuesday, July 2, 2013.

- I worked with 1 male animation participant.

Importance: I am able to save some artwork with the participants permission.

Tuesday, July 9, 2013.

- I worked with 2 male animation participants.

Tuesday, July 23, 2013.

- I worked with 2 male animation participants.

Tuesday 30

- I worked with 1 female animation participant.

August - 4-6pm

Tuesday, August 6, 2013.

- I worked with 1 male animation participant.

Tuesday, August 20, 2013.

- I worked with 1 male animation participant.

September -2-4pm

Tuesday, September 3, 2013.

- I worked with 1 male animation participant.

Tuesday, September 10, 2013.

- I worked with 1 male animation participant.

Friday, September 20, 2013.

- Annika wrote an e-mail that she has confidence in my project, saying that I have a very pleasant and sensitive and respectful attitude towards the patients. See e-mail in appendix.

  Importance: It is necessary for my research that I get support from the professionals that I work with. Without their trust in me I would not be able to do this research. Networking is a large portion of making the research possible.

Tuesday, September 24, 2013.

October – 2-4pm
Tuesday, October 1, 2013.
Tuesday, October 8, 2013.
Tuesday, October 15, 2013.

Tuesday, October 22, 2013.

- I worked with 1 male animation participant today.

  Importance: When I work with one interested participant, they can take up most of the 2-hour session. See journal entry.

Tuesday, October 29, 2013.

- I worked with 1 male animation participant today.

  Importance: This participant was using images from the internet in his animation. He also wanted me to help him play with the electronic drum kit. See journal entry.

November - 2-4pm
Tuesday, November 5, 2013.

- Photoshop Elements is now available on 2 of the computers.

Importance: The participants can now work with both applications and I can work with 4 participants at a time. The participants can now use digital objects that they have made in Photoshop within their animations.

Monday, November 11, 2013.

- I did the workshop without any supervision today. One of the patients accidentally locked himself in the DJ booth.

  Importance: Even though the Hub only opened in February and is considered to be state of the art there are still difficulties operating some of the features. It felt different to be working with the patients without any supervision. I did not feel alone because there are many nurses and the administrative team around. See journal entry.

Monday, November 25, 2013.

- I worked with 2 male participants doing animations, see journal entry.

  Importance: I am seeing the limitations of working at the computers and with Flash animation. I am looking forward to working in Photoshop with the participants.
  Tuesday 26

December - 2-4pm
Tuesday, December 3, 2013.

- I worked with 1 female animation participant today.

Tuesday, December 10, 2013.

- I'm getting ready for winter break in San Francisco with my family. Autumn term ends.

2014

January - 2-4pm

Tuesday, January 14, 2014.

- Spring term begins.

Tuesday, January 21, 2014.

- No participants today.

Tuesday, January 28, 2014.

- No participants today.

February - 2-4pm

Tuesday, February 4, 2014.

- No participants today.

Tuesday, February 11, 2014.

- I helped some participants do a storyboard for an animation.

Tuesday 18

- I helped patients do arts and crafts.

Tuesday, February 25, 2014.

- No participants today.

March - 4-6pm

Monday, March 10, 2014.

- I worked with 1 male and 1 female participant doing AAPC and 2 male animation participants. See journal entry.

Monday, March 31, 2014.

- I worked with 2 animation participants. See journal entry.

  Importance: One of the participants wanted to download a free 30-day trial on his tablet so that he could have it to work on in the wards. It would be helpful to have tablets available for the patients to use at bedside.

April -1-3pm

Monday, April 8, 2014.

- I worked with 2 female family members of a cancer patient on AAPC and 1 male participant on animation. See journal entry.

  Importance: The 2 cousins of a cancer patient wanted to participate. They were both TYAs. I included them in the study because carers and family members contribute to the health and wellbeing of the cancer patient.

Monday, April 15, 2014.

- I began a conversation with Annika about getting NHS R&D approval to do research for digital arts-based research methods.

  Importance: This is the first step to becoming an NHS researcher in addition to a Goldsmiths PhD researcher.

Monday, April 28, 2014.

- Spring term at Goldsmiths begins.

May - 1-3pm

Tuesday, May 6, 2014

- I worked with 1 male participant on AAPC.

Tuesday, May 13, 2014

- I worked with 1 female participant on AAPC.

June - 1-3pm

Tuesday, June 3, 2014.

- I worked with 1 female participant on AAPC.

Tuesday, June 10, 2014.

- I worked with 1 male participant on AAPC.

Friday, June 20, 2014.

- Goldsmiths summer term ends

July - 1-3pm

Tuesday, July 8, 2014.

- I worked with 2 female participants on AAPC

Tuesday, July 22, 2014.

- I worked with 1 male participant on AAPC

Monday, July 28, 2014.

- I worked with 1 male participant doing AAPC. This participant was working with worrisome imagery and I needed to report it to my supervisor. See journal entry.

  Importance: I was advised to write up a summary of what it was like to work with this participant and send it to Laura Brown, the ward sister. Through working with the participants' I am becoming connected to different medical professionals on the ward.

August - 2-4pm

- I am taking the month off for summer with my family.

September

Tuesday, September 23, 2014.

- I worked with 1 female participant on AAPC.

Tuesday 30

- I worked with 1 male participant on AAPC.

October - 2-4pm

Tuesday, October 7, 2014.

- No participants today.

Tuesday 14

- I worked with 1 female participant on AAPC.

Tuesday, October 21, 2014.

- No participants today.

Tuesday 28

- I worked with 1 male participant on AAPC.

November - 1-3pm

Tuesday, November 4, 2014.

- No participants today.

Tuesday 11

- No participants today.

Tuesday, November 18, 2014.

- I worked with 1 male participant on AAPC.

December - 1-3pm

Tuesday, December 2, 2014.

- No participants today.

Tuesday, December 9, 2014.

- I worked with 1 male participant on AAPC.

2015

January - 1-3pm

February - 4-6pm

Wednesday, February 11, 2015.

- R&D approval

Importance: I am now an NHS researcher. This clearly defines the context of this research in the clinical environment.

March - 1-3pm

Monday March 23, 2015.

- I worked with 1 male brain outline participant and 1 female brain outline participant.

April - 4-6pm

Thursday, April 23, 2015.

- 1 male brain outline participant
- 1 female outline participant
- 2 female hands outline participants

Importance: I am able to work with more participants at a time using this format.

Thursday 30

- 2 female outline participants.

May - 4-6pm

Thursday, May 7, 2015.

- 2 female brain outline participant.
- 2 male brain outline participant.
- 2 female outlines participants.
- 1 female double profile participant

Friday, May 15, 2015.

- I participated in Goldsmiths Annual Researchers Day. Round table 1: Engaging Science – Chair: Dr John Drever, Music.

Importance: I had the opportunity to present my research with different but related academic colleagues.

Thursday May 21, 2015.

- 1 female brain outline participant.
- 1 male brain outline participant.
- 2 female outlines participants.

June - 4-6pm

Thursday, June 4, 2015.

- 2 female outlines participants.

Thursday 11

- 1 male brain outline.
- 1 female double profile outline.
- 2 male double profile outlines.
- 2 female front back head outlines

July - 4-6pm

Thursday, July 22, 2015.

- 1 female head outline.
- 1 gender-neutral outline.
- 1 male brain outline.
- 1 female outline.

Wednesday, July 29, 2015.

- 1 female brain outline.
- 1 female outline.

Thursday, July 30, 2015.

- 4 gender-neutral outlines made by 2 participants.
- 1 female hand outlines.

August - 4-6pm

Monday, August 3, 2015

- London summer Intensive 3 – 31.

Friday 15

- I passed my upgrade.

September 21 - September 18, 2017 Goldsmiths maternity leave

2017

March - 4-6pm

Thursday March 2, 2017.

- I attended Digi UK Enhancing the Patients Journey event. See appendix for CPD certificate.

  Importance: I interacted and networked with key professionals in the NHS. I met the director of NHS digital and the NHS Choices website. I was able to ask her how to get an application reviewed to be featured for patient use on the website. I was able to listen to key speakers about new digital innovations and applications that interact with patients in a variety of health and medical settings.

Thursday, March 9, 2017.

- 1 female life-size collage body map participant. See journal entry.

Friday 10

- Goldsmiths Graduate School Fund awarded me £493.50 to build art therapeutic software with computing students at Goldsmiths.

  Importance: Receiving these funds is a great honour for me. It represents recognition and support in what I am doing.

Thursday, March 16, 2017.

- 2 female A4 collage body map participants. See journal entry.

Thursday 23

- I worked with 1 male participant on an A4 body map.

April - 4-6pm
Thursday, April 27, 2017.

- I worked with 1 female participant on a life-size collage body map.

May - 4-6pm

Thursday, May 11, 2017.

- I experimented with a body map outline with internal organs included. I worked with 1 male participant on a gender-neutral A4 size body map.

Thursday 18
I worked with 1 participant on a life-size collage body map.
Importance: The cut-out collage imagery facilitated more dialogue than the drawn body map.

June - 4-6pm
Thursday, June 8, 2017.

- I worked with 6 participants, 3 males and 3 females, making a life-size collage body map.

Importance: This was the first time that I worked collaboratively with the collage body map concept. It is also the last workshop that I did with the TYAs.

Wednesday, June 18, 2017.

- I close the body mapping workshops at UCLH and stop collecting data.

Importance: I did this because I need to complete my thesis. My studies at Goldsmiths resume on September 17, 2018.

I worked with an estimated 120 participants, 29 of whom did not want to share their data. In total I worked with 91 participants from 2013-15 and in 2017: 43 females, 44 males and 3 gender-neutral. Two different participants made 1 gender-neutral body map each and one participant made 3 gender-neutral body maps totalling 5 body maps. In 2013 - 17 males and 3 females. In 2014 - 14 males and 10 females. In 2015 – 9 males, 23 females and 5 gender-neutral. In 2017 - 7 females, 1 gender-neutral and 4 males.

Re: Thank you!

David Kuper

Fri 5/26/2017 4:51 PM

To:Rebecca Miller <co901rm@gold.ac.uk>;

Hi Rebecca

Very nice to meet you too, and I thought I would briefly summarise our discussions.

I started by explaining to you that under Goldsmiths' new(wish) IP Policy, the College does not claim ownership of intellectual property produced by students in the course of their studies except in certain limited circumstances which don't appear to apply to your situation. The corollary to this is that the College - and in particular the Enterprise Office - doesn't have resources to help commercialise student IP. Accordingly while I was happy to give an informal opinion I was not able to give formal legal advice, and neither the College nor I myself personally can be held liable for this.

I was very interested to hear about your proposal to develop an App incorporating a technique used by Art Psychotherapists called "Body Mapping". From what you told me I doubt what you are proposing would infringe any formal intellectual property rights belonging to a third party that could result in legal action being brought against you. Given the nature of the subject matter, it would seem unlikely that there are patents around Body Mapping. I maybe should have said: it is always possible there are other patents around computer-based art - particularly in the US - but I expect these would cover very specific and specialised software features; I would have thought that the kinds of functionality that you are proposing would be very generic and established so unlikely to infringe these (NB: I should say I am talking from an art-making point of view; I am sure that the implementation of Body Mapping techniques itself is far from generic or established). You are very much planning to implement your own interpretation of Body Mapping and this will not involve copying any substantial part of any other person's copyright work. The term Body Mapping itself does not appear to be a registered trade mark and is almost certainly too descriptive to be protectable.

That said, it is always possible that one of the existing proponents of Body Mapping might take offence, and accuse you of behaving in an unethical manner - albeit this is unlikely to constitute a legal violation. It might be worth you approaching the relevant people to explore this. The fact that you are planning to give the App away for use in the NHS by young cancer victims rather than trying to seek commercial gain should stand in your favour.

Hope that all makes sense, and best of luck with your project.

Best

David Kuper - Solicitor
Goldsmiths, University of London
New Cross
London SE14 6NW
Fax: +44(0) 7919 7773
Mob: +44(0) 7753 661066
Email: d.kuper@gold.ac.uk

Please note I am only 1 day per week at Goldsmiths.

> On 25 May 2017, at 13:30, Rebecca Miller <co901rm@gold.ac.uk> wrote:
>
> Dear David,

Goldsmiths
UNIVERSITY OF LONDON

Graduate School

117 Whitehead Building
Goldsmiths, University of London
New Cross London SE14 6NW
T 020 7919 7774 E graduateschool@gold.ac.uk

33174687

10 March 2017

Rebecca Miller
co901rm@gold.ac.uk

Dear Rebecca,

Re: Graduate School Fund

Thank you for your application to the Graduate School fund.

The panel has met and I am delighted to let you know that they agreed to make a contribution of £493.50 towards the cost of building an art therapeutic app and paying Goldsmiths computing undergrads to assist with programming. **Please note, you are not able to pay participants yourself. Further details below. Also, you (or your participants) are not eligible to claim any of these funds while you are interrupted.**

In order to receive your funding, please complete an expense form (attached), once the expense has been incurred, and send the form together with the receipts to the Graduate School by 31st July 2017. You can return the form and receipts: in person, by post or via email.

Please note that the Expenses Policy, which can be found on the Virtual Graduate School on Learn.Gold, states that claims should be made within eight weeks of expenditure. Please also be aware that if you are paying a helper such as a speaker, they need to complete a speaker claim form which can also be found on the Virtual Graduate School on Learn.Gold.

Congratulations and best wishes,

Yours sincerely

Lesley Hewings

Head of Graduate School Office

Appendix - 4

Installation at Macmillan Cancer Centre in the TYA unit 1/7/2019

Installation at Macmillan Cancer Centre in the TYA unit 1/7/2019

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Glossary

Arts in Health (as defined by Arts Council England's national framework for arts, health and well-being) are arts-based activities that aim to improve individual and community health and healthcare delivery, and which enhance the healthcare environment by providing artwork or performances.[1]

Specifically, arts and health activities can:

- Promote the good health and well-being of communities
- Promote positive health messages and public health issues
- Identify health and well-being needs
- Improve the mental, emotional and spiritual state of Health Service users
- Create or improve environments in healthcare settings for staff and service users
- Help people improve their options for healthcare and support patient choice
- Help medical staff, carers, patients and families to communicate more effectively with each other by offering opportunities for social interaction, involvement and empowerment

Play specialists (as defined by NHS Careers). Play has a special function in the hospital environment, and hospital/registered play specialists lead playful activities and use play as a therapeutic tool. They are neither play therapists nor play leaders.

Play specialists work closely as part of the multi-disciplinary team. Their duties are to:

- Organize daily play and art activities in the playroom or at bedside
- Help children master and cope with anxieties and feelings
- Use play to prepare children for hospital procedures
- Support families and siblings
- Contribute to clinical judgements through their play-based observations
- Teach the value of play for the sick child

[1] Smith, Tom, *An Evaluation of Sorts: Learning from Common Knowledge*, Centre for Arts and Humanities in Health and Medicine, University of Durham, 2003.

- Encourage peer group friendships to develop
- Organise parties and special events
- Provide play to achieve developmental goals

As the job title implies, staff work in hospitals. Some play staff will work in hospices and other community-based settings.

Art therapy (as defined by the American art therapy association) is the therapeutic use of art making, within a professional relationship, by people who experience illness, trauma or challenges in living, and by people who seek personal development. Through creating art and reflecting on art products and processes, people can increase awareness of self and others; cope with symptoms, stress and traumatic experiences; enhance cognitive abilities; and enjoy the life-affirming pleasures of making art.

Art therapists are professionals trained in both art and therapy. They are knowledgeable about human development, psychological theories, clinical practice, spiritual, multicultural and artistic traditions, and the healing potential of art. They use art in treatment, assessment and research, and provide consultations to allied professionals. Art therapists work with people of all ages; individuals, couples, families, groups and communities. They provide services, individually and as part of clinical teams, in settings that include mental health, rehabilitation, medical and forensic institutions, community outreach programmes, wellness centres, schools, nursing homes, corporate structures, open studios and independent practices.

The Hub at UCLH The Teenage and Young Adult Service is based in a specialist unit on the third floor of the Macmillan Cancer Centre University College London Hospital and receives funding and support from the Teenage Cancer Trust. The unit provides care, treatment and consultation for young people with cancer aged 13 to 24 years. The service is provided by UCLH doctors, nurses and clinical staff and is completely integrated with the inpatient service on the main University College Hospital site. The unit consists of consulting rooms, treatment areas, and a recreation area known as the Teenage Cancer

Trust Hub, which has been designed and based on the suggestions of young people. The Hub includes a gym, DJ booth, computer gaming space, education zone and café.

Ambulatory care is a patient focused service where some conditions may be treated without the need for an overnight stay in hospital. You will receive the same medical treatment you would previously have received as an inpatient. The aim of this service is to provide you with the care required to treat your condition during scheduled ambulatory care opening hours. You will be able to return home and if further treatment is required you will be asked to return to the unit to receive this.

Acronyms

Abstract auto portrait collage (AAPC)
Digital art therapy (DAT)
Digital collage (DC)
Teenage and young adult (TYA)
Adolescents and young adults (AYAs)
Co-design (CD)
Narrative analysis (NA)
Digital visual ethnography (DVE)
Body mapping (BM)
Constructivist grounded theory (CGT)
Grounded theory (GT)

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