DIGITAL DEATH:
THE MATERIALITY OF CO-CRAFTED LEGACIES

Stacey Pitsillides

Thesis submitted to Goldsmiths, University of London
for the degree of Ph.D. in Design

Goldsmiths
UNIVERSITY OF LONDON

2017

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.

Stacey Pitsillides

ACKNOWLEDGEMENTS

ABSTRACT

Our relationship to death is changing. The prevalence of death and dying online has created new ways of understanding those we have lost. This includes the diversification of aesthetics traditionally associated with mortality. Online environments have provided new opportunities for interacting with the dead, putting the theory of continuing bonds into practice but also creating a data boom that is an overwhelming digital legacy. The question of how we can make meaning from the things left behind will explore the entanglement of people with data, documents, traces, things, collections and archives both online and in our homes. This develops an understanding of materiality that considers the digital as a unique material, incorporating the affordances of digitality into our experiences of personal collections. It uses crafting, narrative and curation to draw these collections together, offering a plurality of experiences and aesthetics.

In association with The Hospice of St Francis, this research uses co-design as a methodology for constructing three unique collaborations between the bereaved, a creative practitioner (art therapist or designer) and the collection itself. These collaborations create an emergent process for exploring the qualities of inherited things. The co-design process informs the use of materials and concepts, with the aim of creating meaningful artefacts for exhibiting. The participants are able to steer the overall direction and focus of this practice research from the first session, narrating the collection to the final construction of crafted responses. It follows through into the public exhibition where the use of language, curation and aesthetics are developed collaboratively. This research can be applied to hospices developing a creative and digital agenda, in addition to public engagement through the collaborative exhibition. It also has strong relevance to the fields of art therapy and co-design, bringing them into conversation and sharing methods.

TABLE OF CONTENTS

LIST OF FIGURES

RELATED INFORMATION

Italics – is used in reference to titles of art works, books, games, project titles, websites, articles, conference papers et al.

Underline – is used to show glossary terms (These terms can be found in App.6).

Bold – is used to show the design lenses.

Bold Italic – is used for exact words that are mentioned in interviews and design sessions but are not full quotes.

'Single Quotes' – are used to designate key terms used throughout PhD that are derived from books, papers or online.

«Guillemet» – are used for research questions and questions that have occurred during the research process.

Note: the four practice films using the interviews from Appendix 5 can be found in the USB pocket.

INTRODUCTION

Context of Research

Digital death shifts our perception of mortality through online environments. It instigates an inquiry into death that considers our interaction with legacy. Digital death research was initiated in the 1990's with two seminal papers by Roberts (1999), who explored grieving through cemeteries in cyberspace, and Sofka's (1997) observation of caskets for sale on the internet. This thesis uses the concept of digital death and the community that has expanded around it to explore the relationship between bereavement and materiality and how it may be extended to include digital things.

Research into digital death has been developed alongside an increased interaction with social media. From 2009 onwards we see the growth of an interdisciplinary community of academics, industry leaders and members of the public who are interested in death. Increasingly these research strands have been unified under a number of terms including 'Digital Death', 'Technologies for End of Life' and 'Death Online'[1]. As an interdisciplinary community it focuses on unifying innovative knowledge and using the range of expertise to expand the boundaries of digital death research. The term 'Thanatosensitive Design' introduced by Massimi (2009) also signifies a shift towards design that engages in a sensitive way, with death and dying. It allows researchers to explore and reflect on how design research engages with vulnerable groups (Vines et al, 2014).

For this thesis the title is located at the crossroads of bereavement, crafting and digitality. Therefore an exploration of things and collections create an approach to legacy that does not focus explicitly on digitality but draws it into dialogue through craft and making. It is worth noting that there are a number of international research projects that explore the digital and materiality, revealing

---

[1] In early 2009, when I initiated my research within my BA in Design, a search in Google Scholar of the keyword "Digital Death" (appearing together) produced only 44 results of which only one article (Lucenet, 2002) actually refers to the term but in an opposite context (preservation of digital heritage). In 2016 when using the same search criteria we have a significant rise in research with 421 results, many of which being relevant works from within these research communities. Other terms also provide strong indications to the development of this research with "Death Online" receiving 805 results and "Technologies for End of Life" 48 results. This mirrors the development of specific conferences in Death Studies, Human Computer Interaction and interdisciplinary research conferences such as the *International Death Online Research Symposium*. For three consecutive years (dates: 2010, 2011, 2012) the Conference on Human Factors in Computing Systems (CHI), the premier international conference on human-computer interaction, has hosted a workshop on *Technology Design at the End of Life, Death & Bereavement*. In addition to this the *Centre for Death and Society* (CDAS) has hosted two conferences (dates: 2011, 2012) on the theme of *Death and Dying in a Digital Age* and *DORS* has run for the past two years (Durham: 2014, Kingston: 2015, upcoming Aarhus Denmark: 2017). These events have acted as a platform for promoting this interdisciplinary research.

relationships between data, digital images and coded materials, for example the *Material Codes: Ephemeral Traces* project (2016)[2].

Within my own research I identified digital death (Pitsillides et al, 2009) as a terminology that was broad enough to use <u>speculative design</u> to consider; people's death and their representation in digital environments; the death, deletion or loss of digital information; and the simultaneous immortality of digital information and need to engineer its death[3]. To understand how digital death is perceived today, it is important to briefly chart the milestones for the technology industry, as most of our online systems were designed without considering death. For social media this was particularly poignant, as profiles of the dead would ask to reconnect with you, prompting users to question the uncanny placement of this <u>agency</u> along with their own mortality. In 2009 I also created a series of short films called *Rest In Pixels*[4] which envisioned how social media could be redesigned in a death conscious way. This included the fictional introduction of a Twitter obituary, Facebook inheritance, deletion and black profile mourning mode and a service in Second Life that blends the pixels of the deceased person's avatar into this virtual environment. The industry soon followed suit. In 2010 Facebook introduced its *Memorial Mode*, which strips the profile of all active components so it does not age and cannot add new friends. In 2013 Google's *Inactive Account Manager* was introduced. This allows users to designate what will happen to all their Google networks after they die. In 2015 Facebook introduced another feature, the creation of a legacy contact to manage your account after death.

Although these are not finished systems they do begin to address some of the complexities around keeping and inheriting digital things. To help people cope with the complexity of this inheritance or management, bloggers have formed a core part of a digital death research community with key players such as *Digital*

---

[2] Material Codes: Ephemeral Traces is a three-year research-creation project funded by the Fonds de recherche du Québec – Société et culture (FRQSC): http://www.materialcodesephemeraltraces.com/ [Accessed: 26th October 2016]

[3] This was introduced within the paper: S. Pitsillides, S. Katsikides, M. Conreen "Virtuality and Society" International Workshop on Images of Virtuality: Conceptualisations and Applications in Everyday Life. *Digital Death*, IFIP WG9.5, April 23-24, 2009, Athens, Greece. Accessible at: https://issuu.com/stelios_giama/docs/iov09_proceedings (p. 131 - 143). [Accessed: September 26th 2016].

[4] The *Rest In Pixels* film collection can be accessed on Vimeo: https://vimeo.com/album/102363. [Accessed: September 15th 2016].

Dust[5], *The Digital Beyond*[6] and *Social Embers*[7] keeping the community up to date on media coverage, activism and start-ups in this sector. The open *digitaldeath* mailing group (initiated in May 2010 through the first *Digital Death Day* in Mountain View, California) is another important source of information and discussion. It is a place to share new research but also quickly crowd-source a range of answers to any question. The community has grown to over 200 members, showing the rising level of interest and fertility of this research area. I was one of the founding members of this group and ran three *Digital Death Day* unconferences[8] (from 2010 – 2012). Another network that has emerged from this is the *International Death Online Research Symposium* (DORS) that has developed three academic conferences. I was the co-convener of the 2nd DORS conference (2015), which we are developing into a Special Issue on *Networked Emotions: Interdisciplinary Perspectives to the Remediation of Loss Online* for the Journal of Broadcasting and Electronic Media. This interdisciplinary community has created a research agenda that pushes at our current perceptions and practices around death and dying in the 21st century. It sits within conversations around digitality and how our engagement with digital things is changing us. The commitment to interdisciplinarity itself, to openness and inquiry is of great importance to understanding and designing within this area. It creates new ethical challenges for public engagement through design but also opens up new possibilities for creativity.

Research Stories

Within this research, as a reader, you will find a range of stories. These are the stories of people, places and things. They speak to the curatorial and crafting dilemmas approached within this thesis that are framed by both theory and context, aiming to give you not only an academic grounding of this research but

---

[5] *Digital Dust*: http://digital-era-death-eng.blogspot.co.uk/. In *Digital Dust* Vered (Rose) Shavit uses her blog to chart "Death in the Digital Era & Life After Death on the Net: the Digital, Virtual and Online Aspects of Current Death". [Accessed: September 15th 2016].

[6] *The Digital Beyond*: http://www.thedigitalbeyond.com/. In The Digital Beyond, Evan Carroll and John Romano give information about your digital existence and what happens to it after your death. On their about page they claim to be a "go-to source for archival, cultural, legal and technical insights to help you predict and plan for the future of your online content." [Accessed: September 15th 2016].

[7] *Social Embers*: http://socialembers.com/. On her blog, Sandy Weatherburn states that she "founded Social Embers to carry out research into digital estate management, internet afterlife, digital footprints, and can provide support, advice and training in aspects of digital bereavement and digital estate planning, which is becoming increasingly important in the digital age." [Accessed: September 15th 2016].

[8] Kaliya Hamlin introduced me to the unconferencing model. Unconferencing seeks to use principles of self-organisation and collaboration to create a conference where interdisciplinary groups can come together and collaboratively consider complex problems. It subverts the traditional academic conference model as everyone who attends can host a session or draw a group together around a particular issue. http://unconference.net/unconferencing-how-to-prepare-to-attend-an-unconference/. Kaliya Hamlin, one of the founders of the *Internet Identity Workshop* also instigated and facilitated the first *Digital Death Day*, following the death of a prominent member of their Identity community. I followed this model running two Digital Death Day's in London and one in Amsterdam in collaboration with the Tropenmuseum's *Death Matters* Exhibition. [Accessed: September 21st 2016].

also to engage and animate it; retaining the life of the practices, which have constructed this knowledge. By recounting the holistic experience of practice in a subjective way, the relationship between meaning and making is developed around the highly charged topic of death and bereavement. The story is a written form of practice that responds to the challenges of co-design as it documents and reflects what happened within the sessions and evaluates the interviews, using the craft of writing to highlight individuality rather than drawing out themes that can be applied more generally to the experience of making as a response to death. It is in this way that the research does not attempt to build universal knowledge but rather to listen, create and put into action a process of making that could be expanded through repetition, scaling and adapting (Barrett and Bolt, 2014) rather than creating fixed principles, processes or specific modes relating to bereavement and creativity.

This research goes beyond the clinical details or empirical evaluation often involved in hospice based research and deals with death and loss in a 'designerly way'[9]. This involves a material crafted approach to research (developed in Chapter 4) that draws together the threads constructed through doing the sessions, ethics, practice and engaging with the research site at The Hospice of St Francis. Informal conversations with art therapists, St Francis support staff, St Francis bereavement councilors, St Francis research governance[10] and the bereaved themselves developed this research in a live way. Their narratives drive the research, mirroring the narrative turn in hospice care. Gunaratnam and Oliviere (2009) describe this as a validation of patient experience and state that it has potential to readdress the balance between "psycho-dynamic and artistic methods" (p.2) but must also be evaluated critically in terms of its usage of people's stories and in this research's case the works produced. Here the stories are woven into practice, rather than being used as a means of altering services, and facilitate the bereaved in crafting stories through a range of mediums that feel appropriate to their loss.

This thesis will follow a chronological structure. It will help readers to follow and understand the way the research unfolded and changed based on ethics,

---

[9] As described by Nigel Cross (2001) in his article *Designerly ways of knowing: design discipline versus design science*, there is a shared affinity between designers and the human-made world of artifacts and it is in this way, rather then through 'the sciences of the artificial' or the technological that they are able to reconstitute and contribute to the maintenance and creation of that world. He advocated that along with using methodologies adapted from the sciences and the arts, that it is important that design builds its own intellectual culture, on its own terms.

[10] The Research Governance Framework is used within health and social care to "outlines principles of good governance that apply to all research within the remit of the Secretary of State for Health." Research Governance Framework for Health and Social Care (2005) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/139565/dh_4122427.pdf [Accessed: 24th October 2016]

recruitment and the practice (as discussed in Chapter 3). What was envisioned as a predominantly digitally focused research on «What happens to people's data after they die?» has evolved into a material investigation that incorporates digitality into this wider inquiry. It uses digitality both as a material within the making process but also as a way of incorporating an edited selection of things from the archive into the final <u>artefacts</u>. Although this research has worked with three participants over a period of two years and all their stories will be given equal weighting in the final exhibition and evaluation, it is Freda and her story that have emerged as the main protagonist during the process. By focusing on working with Freda through her husband Victor's death this research will unveil the social, technical, narrative and curatorial structures that have shaped this research practice and reveal new knowledge for co-designing with the bereaved.

Research Questions

There is one key research question that has framed this inquiry,

> «how can collections of things (objects and data) be used as material to embody the relationship between the living and the dead?»

This is answered through the creation of a material approach to investigation within an artistic practice, incorporating the opening up of design to include participation and invite collaborations through co-design (Chapter 4). It is contextualised through voices attempting to disentangle the meaning of art in <u>art therapy</u>, considering how design works with vulnerable people, that sparks off an increased consideration of morality and ethics within the design discipline (Chapter 3). Additionally, the research sits alongside developments that use the <u>continuing bonds</u> theory to open up people to a continued relationship with the dead and a narrative exploration of their place in our lives. This emphasis on narrative construction of a durable biography has become integrated into new approaches to therapy and celebrancy (Chapter 1) as well as new services and platforms online, which store narratives and assets of the deceased. The increasing number of things collected online also impacts how we remember and honour the dead within different media and technologies (Chapter 1). The understanding of things is explored through literature and the relationship between collections and archives, creating a range of lenses supporting the development of this research practice (Chapter 2). Narrating, editing and making forms the backbone of this investigation with the things becoming mediators of these actions and informing a process of translation through practice (Chapter 4). The way these things are translated into a final outcome uses design methods

applied within studio practice such as: selecting, narrating, sketching, ordering, conceptualising, editing, translating, curating, making and framing in order to help participants move from collection to exhibition (Chapter 4 and 5). The use of co-design within this context is important as it aims to balance not only the relationship between the designer/artist and the participants but also the relationship between the researcher and all other parties. It seeks to express the research through exhibition, by making collaboratively with three participants over two years. Public engagement enables contemporary reflections on death and making in response to loss. This helps to open up the research so it can have a wider impact without diminishing the individual approach to collaborations and relationships (Chapter 6). The aim of the research therefore is not the creation of a service to be implemented but an exploration of how services could be grown or adapted in light of current developments within therapeutic and creative practices. Other research questions have evolved through the course of this practice research and you will find them referenced again where they naturally occur (p.142 – p.143).

Value of Research

By engaging with diverse art and design methods, this research shows from the outset how incorporating flexibility and collaboration into practice research can reconsider the role of design in challenging sites. The co-design of artefacts through crafting and making provides new ways of understanding and examining bereavement that engage with contemporary understandings of death – such as the death positive movement[11] and the hospice's role in helping people deal with their digital legacy[12]. Through this it also answers Friedman's and Stolterman's appeal (2014) using design to work fluidly in the boundaries of artefacts, structure and processes. The collaboration itself provides new modes for practitioners to ethically care for vulnerable people at every stage of the research that goes beyond current systems of ethical approval and research governance. This care and respect for participants as collaborators is used to co-curate an exhibition. The exhibition will engage with the public providing new aesthetics, stories and lenses for thinking about death and dying. It also sets a precedent for co-curation as a form of ethical practice. Art therapists may also find the research useful as it provides points of reflection on the relationship between art, materiality and making with the bereaved. These collaborations show the

[11] http://www.orderofthegooddeath.com/death-positive. [Accessed: September 4th 2016].
[12] http://digitallegacyassociation.org/about/working-with-hospices/. [Accessed: September 4th 2016].

importance of the materials used as a way of thinking through the dead and constructing their role in our lives.

Identifying the Communities

Art Therapy

Art therapists have been core to this practice research. As a community of engagement they have been consulted in relation to the development of the methodology and participated directly in the research as participant, practitioner and clinical supervisor. This has provided a strong grounding for the introduction of design and artistic methods. By collaborating, the process has been used to identify diverse methods that establish the use of art and design within hospice settings. In terms of ethics it has also helped me to examine, situate and diverge my practice from art therapy. In application, the main shifts included not recording the sessions and focusing on the notion of studio enquiry and artefacts produced, as opposed to the emotional development (however as can be seen from the evaluation Chapter 5, all participants cite some level of emotional development). By using contemporary and divergent forms of art therapy such as Moon (2010) that consider art therapy as a material investigation, this thesis may provide points of reflection for this community creating more interdisciplinary exchange.

Hospices

The Hospice of St Francis has been embedded within this research since our introduction to one another in 2012. They have worked with me on the ethics and recruitment of my participants. Working through these two stages has highlighted some of the issues in introducing co-design into such ethically rigorous environments but also the benefits for participants when collaborations are successful. The hospice sector will see many developments with the growth of digital things and co-design can provide new modes of approaching this with agility. However it is key to understand and be sensitive to the structures and community of the site, therefore working with hospices on long-term projects that also aim to evolve the ethical structures could begin to address this. It would also open hospices up to further practice research and public engagement.

Participants

The participants as collaborators have been integrated into this research in a number of ways. Firstly their homes are used as sites for the research,

transformed into art/design studios for the duration of the research. In addition to this their specific archives, relationships and interests have helped to construct an approach to making that explores notions of materiality, reframing the dead in our lives and simultaneously exploring themselves in the process. The participants have been involved in constructing the research and considering the meaning of what they are making in a wider context through exhibiting. This experience has allowed them to grow as individuals and understand their loved ones in new ways (see Chapter 5 for full descriptions).

Ethical Research Practice

Defining the role of ethical practice has been a main concern within this thesis and emerged as a unique strand. This includes the legal, practical and creative dimensions of ethical research. It is clear that, when embarking on research about bereavement and working closely with people who have experienced it, the question of how you protect and care for these people will underpin this research. However, it has also been key in determining the timeline, language and communication of the methodology particularly in interdisciplinary contexts. It opened up this research to wider discussions within both institutions, hospice and university, in regard to how practice research functions within these settings. Part of the negotiation with The Hospice of St Francis as the host site for this research was a period of consultation with their clinical team. The consultation aimed to prepare the research for any ethical complications or distress caused to the participants involved. Questions of validity were also grappled with, as the differences between the team's own experiences of research methods and the contrast to design research became apparent. In relation to supporting the validity of the research I was required to employ a clinical supervisor to mediate the ethical concerns within this research from a clinical perspective. The nature of these sessions is discussed in depth in Chapter 3. They helped profoundly by focusing not only on ethics but also on getting to know the hospice sector and managing the emotions involved in practice research. The practitioners recruited shifted from practicing artists, designers and makers to art therapists with their own active artistic practice. This shift impacted the research goals and allowed for deeper reflection on the ways artistic practice is currently being positioned within the hospice setting. The practitioners were able to reflect on some of the concerns and challenges for the developing field of art therapy.

In the university setting the concerns were more focused around how the university positions itself in relation to this research, including whether the ethical

approval forms are robust enough to deal with the complexity of the research. This was prevalent when working with people outside the institution, particularly those classed as 'vulnerable' within an ethical context. This included navigating the tickbox ethical procedures through practice research, which can offer new insights and opportunities for thinking about ethics, transforming the termed 'vulnerable' participants into collaborators as discussed in Chapter 3 and 5. It led to questions around how the university deals with liability in research initiated by their students and to a discussion with the Goldsmiths' Ethics and Integrity Committee and its officer Muriel Swijghuisen. This conversation centred on the question of who holds the liability when working in the home and coordinating a team of art therapists. In addition to this, regular reports to the Graduate School at Goldsmiths helped the level of understanding in regard to how time was seen in different scales within the university and the hospice, and the pace of recruitment based on the hospice's own systems of engagement. This thesis did not originally aim to explore ethics in relation to practice research but it has become a fundamental part, critically reflected on within the evaluation (Chapter 5). The contribution to knowledge in this sector, including how challenges were woven into the design of practice, will be expanded on in Chapters 3 and 6.

Design Research and Modes of Practice

Design research frames this approach to inquiry by developing new modes of practice through co-design and producing knowledge through the forming of artefacts with live methods (Back and Puwar, 2013). As this research began to recruit participants, the role of the design and artistic methods solidified. Before recruitment it was very difficult to intellectualise the way that flexibility within the sessions would inform the co-design process, but as discussed in Chapters 5 and 6 it creates a rich process of collaboration through narrating, selecting appropriate materials, conceptualising and making within the home. In these home sessions, the home becomes a kind of extended studio or design space. By using situated design methods I am able to position an approach to making with things and people that moves fluidly between thoughts, feelings and tacit interactions with materials and making. The main knowledge within this research is produced through making and forming the artefacts themselves, not extracting or distilling themes from observation or interviews. Interviews are used to support participant's reflection on the process and this is then woven back into the making and curating of the exhibition. Short interviews focus on what has been gathering at the surface through the conceptualisation produced by the making process rather than trying to reach a deeper inquiry about the

psychological or emotional impact of taking part. The use of co-design as a specific form of design research is key to the practice as it navigates the risks involved in working with partners, working with the bereaved and working through ethics, with an understanding that the research would have to form as each process solidified. It also has to build in elements of the collaboration that help to craft research questions as an integrated part of the research. The reader will find a detailed discussion of this on p.143, which distills the way that a top to tail co-design process was used. While it is not my intension to tell people how to do their practice the use of a holistic approach to co-design that involves participants in all stages of the research development, transforming them into collaborators offers a range of opportunities for other researchers to use as a base. It sets the ground for seeing ethics, research questions, practice and exhibiting as part of the co-design. By following the research through collaborating I am using the qualities of crafting, where a research process is approached as raw material with a range of unfixed potentials (Alfondy, 2007), and that outcomes are not pre-packaged into specific design outputs or limited by the researcher's own proposed outcomes.

Public Engagement

Co-design is increasingly being considered as a good fit for the development and reform of public services. This responds to the need for a greater degree of individualisation, where collaboration provides a more holistic view of the experience of systems and their usage (Bradwell and Marr, 2008). However, using co-design as socially engaged research can be challenging, particularly within rigidly regulated environments such as hospices. When the government does not instigate this, researchers need a nuanced approach to ethical negotiation and approval (Goodyear-Smith et al, 2015). Public engagement can also be approached creatively within events, galleries and sites where people can gather. These spaces can provide open forums for sensitive debate that challenge current preconceptions. For example, *Death: The Southbank Centre's Festival of the Living* (2012) was a sold out 2-day weekend, which covered a wide range of themes from natural burial to digital death. In addition to this, current events like *FutureFest* see the inclusion of *Love After Death* as a futuring topic (September 2016, App.1) and Sutton House, as a heritage property, includes a lineup of events, installations, workshops and an exhibition on *Life.Death.Whatever* (October 2016). This shows the public and creative and cultural industries' desire to engage with these challenging issues openly, considering the relevance of mortality in the 21st century. Frandsen and Petersen (2014) also state that "in

recent years on an international level we have seen a growing interest in the power of design and art as tools to improve participation and civic engagement" (p.182). Here, civic engagement is not only used to break down some of the taboos around death and dying but also to reconstruct social norms and visual aesthetics, which in turn create new practices. Although death is a theme that artists have always engaged with, it is the artistic and technological mediation of death that opens itself to engaging with many publics, through participation and debate.

Chapter Outlines

Chapter 1 will contextualise current approaches to death and bereavement that are informed by our creative, aesthetic and material choices both online and offline. It will chart some of the contemporary developments: from digital memorials to new forms of dispersal that are shaping our current understandings of the dead; showing how developing aesthetics and collections of the bereaved online are helping to enhance the deads' agency; and to construct our continued relationships with them and individualise their continued presence. This chapter will help situate how our digital presence has altered our relationship to the dead, making visible our continued interactions and personal approaches to death and bereavement online. It will provide support for the continuing bonds theory that has given rise to various creative examples of digital memorialisation and bereavement. It will consider how this has been echoed in the creative and cultural industries through the creation of websites, applications and other approaches to dealing with digital legacy and memory storage online. It will also discuss current developments offline and the way that some celebrants and funeral directors are developing a more creative approach to their work.

Chapter 2 follows this contextual chapter and develops a range of design lenses that define and consider the relationship between material things, data and context. It explores the role of digital and physical things within this inquiry and expands on how our experience of them shifts when they are placed in collections or archives. It critiques current trends towards saving everything online by considering the impact of digital overload to people's posthumous biographies and the challenges of finding meaning in such large and decentralised collections. In addition to this, it uses the example of inheriting a collection of thimbles to develop an understanding of collections and meaning making in relation to design and materiality. This examination is further extended through the introduction of key theorists and ideas. These include: Carolyn Steedman's definition of the

'Archives' (2002) in relationship and contrast to Derrida's (1996), Roland Barthes' self-reflection on his collection of photographs (1981), Sherry Turkle's discovery of her father in the 'Memory Closet' (2011) and Edward De Waal's genealogy through the 'Vitrine of Netsuke' (2011). This literature informs a tacit approach to designing with physical and digital archives and collections. It includes an approach to personal curation, as the examples include various ways of framing a personal relationship to loss through the notion of a collection, which is not seen for its material value but as a container for meaning and relationships.

Chapter 3 delves into the background of the research considering the process of building trust and developing understanding within the Hospice of St Francis. It opens up the conversation about ethics, data and anonymity in the digital age, through considering how the evolution of ethics within research alters the nature of the research being undertaken. At the Hospice of St Francis this included challenges of liability, working in the home and the need for clinical supervision in order to gain ethical approval. The clinical supervision also functioned as an important insight into the hospice environment. This insight was particularly helpful when navigating challenges of recruitment, bureaucracy and ethics within the research. Another aspect that will be reflected on within this section is the balance of roles including the shift between facilitator, practitioner, co-curator and researcher. It is important to understand these roles as they help to form the basis of the methodology and allow for the flexibility needed to apply co-design to this research.

Chapter 4 defines the role of co-design and public engagement within this research. It considers this research's engagement with design and artistic methods to investigate loss through the creation of artefacts for exhibiting. It also considers the relationship between art practice and art therapy, defining the differences between co-design and art therapy within this thesis. This is clarified by focusing on producing artefacts, as a core objective of the research, when working with the bereaved. This research also uses crafting as a core process, where crafting may be considered as a flexible and emergent process and can be approached both digitally and physically to drive the creative collaboration. The collaboration between the practitioner and participant has also been developed through a description of the process of working with Freda through the sessions and using conversations about the meaning of possessions and artefacts of the deceased to inspire the making. The main co-design sessions can be catagorised as narrating the archive, getting to know the deceased, sharing inspiration from

other artists and designers, identifying key concepts and mediums to use within the making process and the shared curation of the final exhibition.

Chapter 5 focuses on evaluating the meaning of the artefacts produced by the co-design sessions, from the perspective of the participants and practitioners. It also focuses on what meaning was produced from the process of making, details of materiality and aesthetic qualities. It reflects on the nature of the exhibition as a co-curation, including how to label and discuss the things that have been produced and whether it is important to keep the artefacts or continue the usage. The process of collaboration is also evaluated, including the role collaboration plays as a key strand within the research. As the exhibition will be held in February 2017 it cannot be fully evaluated, in advance of submission; however, there will be a reflection on how the exhibition completes the design cycle and provides a clear ending for the process. This will also consider reflectively how knowledge is expanded through having an exhibition as an output of practice research, including how the communication of the co-design process will be embedded within it.

Chapter 6 discusses the impact of this PhD research on various communities in terms of practice and ethics. It includes how this research has impacted the Hospice of St Francis and will apply to other hospices considering working with design researchers or within the area of digital death. It presents how the research applies and develops the co-design method as a field of design research. In addition to this, it provides new methods that could be applied to the field of art therapy. Another direct impact is on the participants themselves, which has been discussed within previous sections but will be considered here in terms of public impact, both on an individual level and through the exhibition to the wider public. This section will also include a personal reflection on the research conducted and areas of further research, which extend beyond the submission of this PhD.

I.
REFLECTING THE DEAD IN CREATIVE AND DIGITAL PRACTICES

The Personalisation of Death and Bereavement

The way we approach death is constructed[13]. It is constructed through the societies we live in, the social norms and practices we develop, the way we correspond to communities and integrate new technologies. Dying is one of the most personal experiences we will have in our lives and yet our approach to it has been traditionally standardised. This standardisation creates norms for what bereavement and funerals should look and feel like. However, there is a growing move towards questioning whether any models or systems of categorisation still speak to our contemporary understanding of death (Stroebe et al, 2008). Funerals in the UK now have more scope then ever to be a richly personal occasion and design is contributing to this movement through the introduction of new products. The funeral industry is adapting to the contemporary need for more individualised rituals and people's desire to use funerals as a creative opportunity to further embody or understand the lives of the dead in an individual way.

Eco-burials are one example of a specific range of designed products and services that have seen considerable development within the last 15 years (Harris, 2008). They have contributed to a re-languaging of our rituals of death. Simple changes, such as moving from disposal to dispersal, transform our approach to bodies from something to get rid of to a gift for the earth (Rumble et al, 2014). These shifts challenge what the dead mean to us and how bodies and environments merge to create new associations and experiences of death. Eco experiences range from woodland burials where people are laid to rest under a favourite tree to bio-urns that turn you into a tree[14] or mushroom suits that return you to the earth[15]. Cardboard coffins[16] are another ecological choice but rather than using an eco aesthetic they can be printed, drawn on or decorated with photographs to create

---

[13] Bereavement is increasingly being approached from a constructivist perspective; Neimeyer (2005) states that the "new wave of constructivist grief theory is less the product of any particular thinker than the expression of a sea-change in our ideas about the nature of bereavement." (p.27)

[14] The *Bios Urn* (from 2012). The design of this website, which sells biodegradable urns has a strong use of ecological colours, symbols and copy. https://urnabios.com/ [Accessed: 15th August 2016].

[15] *Coeio* (from 2011) is a mushroom suit that decomposes the body as an ecological form of burial and is an example of how design research can become a product within this new market. The website is clean, modern and uses the symbol of infinity, the copy sells the product on its green credentials as a green burial. http://coeio.com/infinity-burial-suit/ [Accessed: 15th August 2016].

[16] *Natural Endings* is a green funeral director. Their website has a natural colour palette with large images of forests that showcase their knowledge of the sector. http://www.naturalendings.co.uk/our-coffins/cardboard-coffins/. [Accessed: 15th August 2016].

a coffin that reflects the body within. This aesthetic varies as we shift from the eco to the handmade, including the highly crafted *Ghanaian Ga Coffins*[17] (Roberta, 2008) that embody the everyday through colorful and symbolic shapes, responding to people's lives, which have become synonymous with their individualism. These coffins have been exhibited to the public at *Death: Southbank Centre's Festival For the Living*[18] (2012) and are often used to inspire the imagination of what a crafted response to death might look like.

Funeral directors can also create sentimental experiences through paying attention to the detail of a person's life. *The Cozine Memorial Group*[19] shared one example of a funeral where the person had been an avid baker and had a particularly favourite cookie that they used to bake. A batch of these cookies was baked for the funeral and given to people as gifts wrapped in the recipe. This sensory experience both embodied the dead and shared the knowledge of the favourite recipe, confirming it as a legacy that was distributed to all attendees. As more people begin to identify themselves as non-religious or explore incorporating a plurality of religious identities that combine and augment existing rituals and practices (Woodhead, 2016) the question of what to do with the dead, both literally and socially, becomes ever more complex. As the digital is something that undoubtedly contributes to our life stories, it is not uncommon for funerals these days to have displays of digital content, slide shows put together from relatives or the person's Facebook page. Technology can even be integrated into the graveyard by placing a QR code onto the grave, either carved or using an adhesive sticker (Gotved, 2015), that allows loved ones to leave and access digital content by scanning the bar code via their mobile phone.

It is clear that moving beyond some of the traditional religious practices associated with death means that there is space for innovation and new aesthetics, but with a vibrant marketplace for everything from DIY coffins to ashes being transformed into diamonds, fireworks or coral reefs to digital safety deposit boxes or technological reanimation[20], we run the risk of immersing ourselves in a choice of products, which may or may not allow for an emotive

---

[17] The *Ghanaian Ga Coffins* (or fantasy/ figurative coffins) emerged around the 1950s. These figurative coffins are produced by master craftsmen and are generally sculpted to resemble that person's occupation, representation or other aspects of their life.
[18] The Southbank Centre's *Death: Southbank Centre's Festival For the Living* (2012) responded to trends of creativity and individualisim within this public event. It also showed the public's readiness for considering new approaches to death and dying. This included the exhibition of Ghanaian Ga Coffins, along side a range of representatives from the funeral industry that people could seek advice from and a full programme of challenging talks, panels and discussions around death and dying. http://www.southbankcentre.co.uk/sites/default/files/documents/Death_Day_Pass_SATURDAY_28_JANUARY.pdf [Accessed: 16th August 2016].
[19] This story is from the *Cozine Memorial Group*: http://www.cozinememorial.com/ [Accessed: 16th August 2016].
[20] Although not all these services have established themselves within the mainstream, the fact that they have established themselves as businesses shows that there is a space in the future for far more diversity within the funeral and afterlife industries.

experience that speaks about that person's life. Having said this, the expanding portfolio of services which can be offered by funeral directors and celebrants today[21] marks a change in the social response to death and creates new rituals that are developing with the digital age (Döveling et al, 2015). *Poetic Endings*[22] shows how this growth and innovation can be used for social entrepreneurship. It offers a celebrant service that starts from the ground up, redesigning what a funeral is for each client. Set up by a fashion design graduate, it shows how commercially (rather then speculatively[23]) the use of design practices can shift people's experience and understanding of the funeral industry. These kinds of re-imaginings of the funeral sector are important as they change the image of this industry and help the public to consider more deeply their needs and desires in relation to creating meaningful funeral experiences.

Continuing Bonds

Continuing bonds can be seen as part of this individualisation of death. From a theoretical standpoint, it marks a significant change in the way that bereavement is defined and engaged with. Continuing bonds theorists have shifted and debated the Freudian claim[24] that bereavement counselling should focus on 'internal bereavement and detachment'*.* Walter and Klass are two scholars that have had a strong impact on the acceptance of this theory (Klass et al, 1996; Walter, 1996; Walter and Klass, 2001; Klass, 2006). They argue that Freud's view of bereavement is limited as it removes much of the complexity, creativity and individualism involved in relationships. Additionally they claim that socially we are moving towards a position where the dead remain present in our lives as sources of guidance, role models and as an embodiment of particular values and life lessons. Neimeyer et al (2006) also contribute to this constructivist approach to bereavement by introducing a process of "constructive reorganization rather than relinquishment of the bond [that] can be achieved by 'internalizing' the lost loved one as an extension of the self" (p.717). This shows how we are built by those we have lost and how the living and dead can develop a correspondence of agency (Walter, 2013). The selection of funeral related products, discussed in the first section, also reflects this by promoting a choice of ritual, process and aesthetic that reflect the life of the deceased and reaffirms their identity after death.

---

[21] Walter (2016) comments on some of the current developments within the funeral industry, August 9, 2016 12.58pm BST. https://theconversation.com/breathing-new-life-into-the-funeral-business-62789. [Accessed: 10th August 2016].
[22] *Poetic Endings* is a funeral service that offers "Funerals of Style & Substance." It is creative funeral service that focuses on meaningful experiences at the end of life. http://www.poetic-endings.com [Accessed: 8th August 2016].
[23] Speculative Design – see Glossary.
[24] In *Mourning and Melancholia*, Freud (1922) developed the first systemic analysis of bereavement, in line with the time period. One of his central claims was that people in bereavement need to move on as an autonomous individuals, leaving the deceased behind and forming new attachments. This was considered as a way of processing their grief and reintegrating into society.

In *A New Model of Grief: Bereavement and Biography* (1996) Walter defines the role of bereavement as the development of a durable biography and ongoing relationship with the dead. This is primarily achieved through talking about the dead and finding a place for them in an individual's life. As these practices are being researched and understood they support the redevelopment of mainstream bereavement care and shift the goals of bereavement counselling to "include a degree of narrative therapy, in which the client works out a story about the deceased and what the deceased meant to them" (Walter, 2009: p.144). By using personal autobiographical experience we can maintain a continued presence of the dead that includes conversations with and about them. This approach to bereavement, where people were asked to narrate the dead and assign them a role in Marwit and Klass's research (1995), was found to be a fairly intuitive process, with most participants enjoying the experience. As a theory, continuing bonds pushes against prior research around stages or generalised theories of grief, including attitudes to what constitutes 'normal' grief or the treatment of pathological grief (Walter, 1996: 12). It aims to put some of the control back into the hands of the bereaved, which will be further developed in Chapter 4 when considering recent developments in art therapy (p.103). This provides a good grounding for using design research methods when working with the bereaved – such as co-design (Sanders and Strappers, 2008) – that promote flexibility, flattening hierarchies and collaboration.

In *A New Model of Grief*, Walter uses a biographical narrative approach to his own research (Gunaratnam and Oliviere, 2009), where he shares his experience of the death of his father. He shows how rituals can be used and appropriated from other cultures where Continuing Bonds is the norm, by describing how a Zimbabwean friend used traditions of the Shona at his father's funeral. Through the acknowledgement of Len Walter as a continuing member of the family it was suggested that funeral attendees should try to keep the spirit of Len Walter alive. The tangibility of this ritual gave Walter the permission to keep his father's presence and was a turning point in both his own bereavement and understanding of bereavement theory. This use of research writing through the lens of personal experience reflects the way that artistic methods attempt to draw out moments of serendipity that develop over many years. In this paper Walter uses "narratives to create and express meaning, to mediate [the] painful and difficult experiences [of losing his father], and to encapsulate the complicated relationships" (Gunaratnam and Oliviere, 2009: pp.4) between himself as a

researcher and the entanglement of his social and material circumstances that have been creatively integrated into his own bereavement.

Continuing Bonds through Technology

The creativity of continuing bonds has been exemplified online where practices of meaning making commonly involve talking to the dead through social media. Researchers have textually analysed comments (Getty et al, 2011; Giaxoglou, 2014; Klastrup, 2015), interviewed those who write to the dead online (Kasket, 2012; Brubaker et al, 2013) and considered the frequency of contact as a signifier of continued usage (Brubaker and Hayes, 2011). Kasket (2012) shows through her interviews with administrators of Facebook memorials how people are intuitively developing a continuing relationship with the dead using "you" to address the deceased. Through the simple use of social networks users are negotiating, constructing and co-constructing durable digital biographies (Walter, 1996; Waler, 2012) in an ad-hoc way. Kasket also shows the relative newness of these practices by making the distinction between previous online forms of expression such as memorial web pages. In these memorials the rituals tended to involve writing and editing a web page about the dead as a singular process, which is specifically created once someone dies. This situates the technological system being used as part of the agency of the dead. It addresses Latour's ongoing dismantling of boundaries that create a "dichotomy between humans and non-humans" (Latour, 1994: 795).

The Facebook page is distinctive as it already has a community presence and is used in a similar way in death, to in life, for direct communication with the person whose profile it is. There is also a digital tangibility to writing on social media. The physical process of this was felt and described by some of Kasket's interviewees (p.66). They expressed a feeling that Facebook could get their messages to the dead. It is this agency that is imparted digitally through the system of writing on walls, in which a response is normally either delayed or not given. The page that was once a centre of communication from you becomes a source of communication to and about you. It feels like an access point. We continue to perform the same action after death as we did in life. We sit down at our computer, write a message and click send. This does not require a two-way action to feel complete (Harper, 2010). After all we are used to waiting to receive a response, sometimes days or months later. We feel we are heard. In this way, digital content has the potential of actually growing rather then diminishing a

person's entity after death and adding another chapter to the narrative of that person's life.

Shifting Practices around Death and Memorialisation

Social media can provide strong support networks that give people the opportunity to construct alternative processes of bereavement than a funeral, including diverse ways of finding out the news and beginning to deal with their loss. It is in this intuitive and practical way that a person's social media account often becomes the centre of community thought, wishes and reflection after someone has died (Roberts, 2012). Digital platforms also play a role in informing people of a death, allowing grief-stricken family members to write a single mass message rather then contacting each person individually. Although online communities have been known to be helpful during the initial phases of death e.g. planning the funeral, grief support and informing more distant friends of the loss, the broader issue of digital legacy becomes increasingly complex when the bereaved begin to face problematic issues such as ownership or privacy (Bellamy et al, 2013). These issues are encountered from vastly different cultural perspectives, value systems and social norms. It is further complicated by the fact that the data can be produced anywhere, exists within a particular online environment (often cooperate, with specific rules). These companies are themselves situated in a particular country with specific laws and the data may also be housed in servers in another country. Defining digital legacy as part of someone's estate[25] localises this digital content and allows it to fall under that person's control. However, as we continue to produce extensive digital collections, the variety of ways that allow for the management of digital legacy must be grappled with. This includes the ethical question surrounding the responsibility of the service providers and the constantly shifting and largely uninterpretable Terms and Conditions that impact the way this data is experienced. This includes whether it can be extracted and how it may be shared or deleted.

---

[25] *Everplans,* an online portal for legislation and advice states that as of 2016, the USA had 19 states that have put forward laws to protect people's digital assets and give the person's family the right to access and manage those accounts after the owner has died. In their breakdown of *State-by-State Digital Estate Planning Laws*, they also include a description of the law, which includes a link to the full bill. The most recent of these being new legislation in Florida and Michigan. In Michigan "the new law specifically states that all digital assets are bequeathed from one person to the next. It also allows digital information, including social media and website accounts, to be treated like other assets after the owner dies."https://www.everplans.com/articles/state-by-state-digital-estate-planning-laws [Accessed: 7th October 2016]. The *European Law Institute* (2015) states, "the digital age has fundamentally changed the way in which we conceptualise, create, capture, and transfer value and define property. In July of 2014, the Uniform Law Commission, in response to these shifts, approved an act to assure that account holders could retain control of their digital property and plan for its ultimate disposition on death." This has been developed into a feasibility study with the University College London (UCL) to consider whether the *Uniform Fiduciary Access to Digital Assets Act* (UFADAA) is a successful blend of law, technology, and social practice: http://www.europeanlawinstitute.eu/about-eli/structure/general-assembly/ga-2015/fiduciary-access-to-digital-assets-feasibility-study-with-ulc/ [Accessed: 7th October 2016].

Although the law and some technical providers[26] are beginning to catch up with the idea of 'Digital Assets', most people do not consider making provisions for how they wish their digital lives to be handled within their Last Will and Testament. This has led to the development of a range of websites offering services which allow users to bypass the traditional legal framework by leaving passwords, documents and other assets directly online and stating particular 'guardians' or 'executors' that would deal with what was left there after death. These sites range in their marketing approach from referring to themselves as the "Swiss bank account for information assets"[27] to brandishing the dramatic tagline "bridging mortality"[28]. They also vary widely: acting simply as a portal to leave your data; having a strong ethic of privacy and property protection; or designed specifically to appeal to people on a personal and sentimental level, often linked to leaving memories or life stories. As these impromptu practices of memorialisation become ubiquitous, death is visibly and publicly being responded to online (Lagerkvist, 2013).
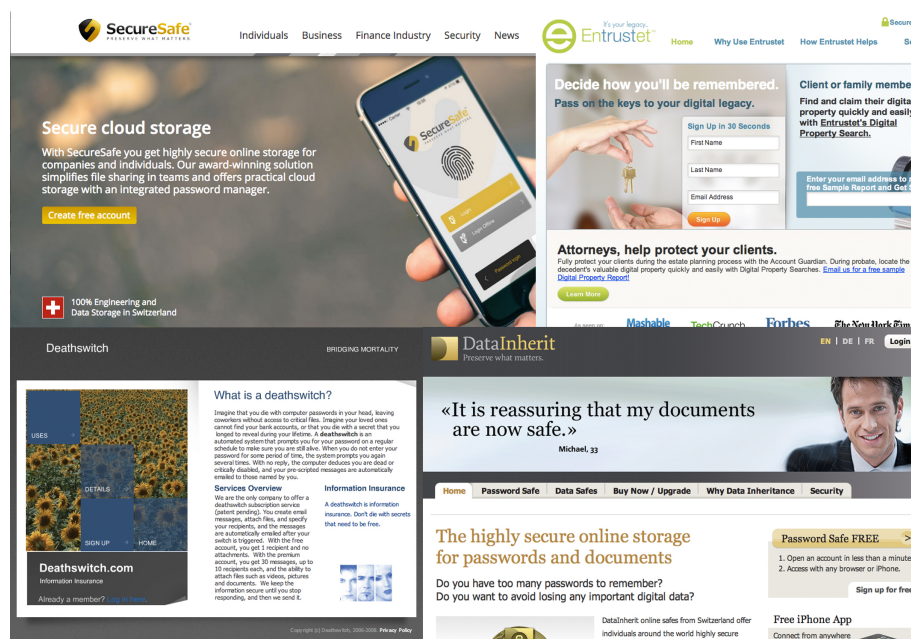
Figure 1: A screenshot of Entrustet and DataInherit, which merged in 2011 to become Safe Secure (from 2008) and Death Switch (from 2006), which no longer exists [Screenshots of Entrustet, DataInherit and Death Switch were taken 5 June 2011, and a screenshot of Safe Secure on the 19 October 2016].

---

[26] Facbook's *Memorialisation Mode*:
https://www.facebook.com/help/103897939701143?sr=1&query=memoriazation&sid=0QSNRhtHC2PqrwaIM [Accessed: 6th October 2016], Google's *Inactive Accounts Manager* http://googlepublicpolicy.blogspot.co.uk/2013/04/plan-your-digital-afterlife-with.html [Accessed: 6th October 2016] & Yahoo Ending (A portal from Yahoo Japan).
[27] *Safe Secure* (2008) http://www.securesafe.com/en/about-us.html [Accessed: 5th October 2016]
[28] *Death Switch* (2006). This website has been taken down but an image of this service can be found in Figure 1.

Although these companies reveal a gap in the legal framework, it is still most common for people to experience death through social media and here they are now familiar with seeing and responding to death online (Walter, 2015). The online space is also very well suited for people who have little experience of personal loss (Gotved, 2014). Here, death can be experienced very well in a non-threatening way through public figures that had a strong impact in your life. The public deaths of celebrities such as Michael Jackson, Robin Williams and David Bowie have inspired a range of responses on social media including re-appropriating phrases from films and songs to commemorate their lives, sharing videos and memories that re-affirm their presence and impact, and the devotion of your status to RIP for a certain period of time[29]. Although the meaning behind these public tributes may be debated, in terms of legitimacy (Riechers, 2012) it is clear that people's visual language of loss is developing and diversifying across these digital platforms, taking into account both the affordances and materiality of these new sites of mourning.

Online there are also many examples that go beyond social media with people responding to bereavement through virtual memorials in personal and individual ways (Haverinen, 2014). A range of gaming platforms have been known to use the particular structure, environment and context of the game in which they knew that person to develop these memorials. An example of this was a tribute to a girl who was an active fighter pilot ace in her favorite computer game: when she died prematurely of leukaemia the other players enacted an online fly-past in her honour (Walter et al, 2012). This has also been particularly relevant in gaming environments such as *Eve Online* and *World of Warcraft* in which appropriate memorials have been constructed to reflect not only the nature of the deceased but the affordances and codes of these specific gaming platforms (Gibbs et al, 2014). In addition to these player interventions in the gaming environments, there have also been games made as specific memorials and empathy experiences such as *That Dragon, Cancer*[30]. This narrative based gaming experience places bereavement on an international stage, allowing for people to experience the story of Joel, the developer's deceased son and messages to be shared by those who knew him, and those who didn't alike.

---

[29]This has also been seen in response to major social disruptions such as the attack on Charlie Hebdo in Paris 2015, with hashtags such as #PrayForParis and the visual use of national symbols (such as the flag) being prompted by social media platforms. This has sparked vivid debates online about the public representation of grief and the role social media platforms play in propagating specific public narratives. News articles such as #PrayForParis: *When Empathy Becomes a Meme* http://www.theatlantic.com/entertainment/archive/2015/11/pray-for-paris-empathy-facebook/416196/ [Accessed: September 28th 2016] give some insight into the scope of this debate.
[30] *That Dragon, Cancer*: http://www.thatdragoncancer.com/#home [Accessed: July 18th 2016]

The Agency of Digital Death
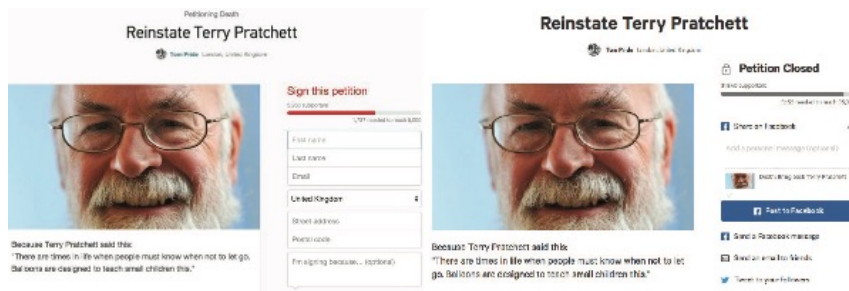
Figure 2: Screenshot of *change.org* campaign *Petitioning Death: Reinstate Terry Pratchett* [2016]

Petitioning Death: Reinstate Terry Pratchett is a good example of how the act of crafting a durable biography can be done in collaboration with online systems. This memorial uses the structure and function of the campaigning site *change.org,* commonly used to start campaigns and contribute to grass roots activism. In this case though it is used to create a fitting memorial for the author Terry Pratchett, who died in March 2015. Terry Pratchett, author of the *Discworld* series, created the character Death as part of his universe and gave him a sense of humour and many human-like qualities. People could sign this campaign and make a personal demand that Death returns Terry Pratchett to us, making it a strong example of the creativity that can be applied to a subversive use of communication technologies in service of public bereavement. The petition closed with 31,845 signatures and adds an element of unintended humour whereby *change.org* as a system automatically increases the goals set in order to prompt more signatures to be added. The target increased over the course of the campaign from 5,000 to 35,000 as more people signed up. In this case however it could be seen as Death making sure that the mortals could not get the better of him as the petition closed just short of its goal, which is fitting to Terry Pratchett's unique form of humour.

This collaboration with the technology shows how the dead can be given agency when merged with online systems and how the materiality of those systems correlate with that person's specific attributes. The digital medium can even be used to build entirely new platforms of ritual, as is the case with *The Johnny Cash Project*[31]. This project incorporates creativity and crowd sourcing by using the song *Ain't No Grave* and very simple digital drawing tools to celebrate and commemorate the life and legacy of Johnny Cash. Fans were invited to reinterpret one single frame of the video by drawing a digital portrait of the man

---

[31]*The Johnny Cash Project*: http://www.thejohnnycashproject.com/ [Accessed: July 18th 2016]

as they saw him and submitting it to become part of a collective video, which when amalgamated embodies a kind of haunting but also touching tribute, with many individual interpretations of Cash. There is also a *You Tube* documentary video[32] attached to the project. It shows people sharing their experiences of contributing to the song and how it confirms their understanding of Cash and adds to his public narrative.

In both *Petitioning Death: Reinstate Terry Pratchett* and *The Johnny Cash Project* a simple way of interacting with the digital medium contributes to a more substantial whole that confirms the presence of these public figures. It is the combination of fans with the digital medium and a strong legacy identity that is of interest to this research. These practices are much richer than simply using narration alone and create a network of human and non-human players (Latour, 2005; Law, 1992)[33] that actively contributes to continuing bonds with these two public figures. This was put to particular use in Pratchett's case as *change.org* is a key player in the function of the memorial. When bereavement is expanded to its use of materiality, functionality and affordances of digital and physical things, we can explore the way that we are enmeshed with our environments and things. In Facebook's case we become the wall that people address thoughts and comments to. This develops new modes of understanding a person and can be expanded creatively to develop diverse accounts and experiences that embody people.

Legacy and Context

Context is of great importance to the meaning of legacy. One of the issues with dealing with digital legacy is that the context is intermingled with systems and people – therefore deciding how to manage a person's legacy can be tricky. The accumulation of this form of legacy is another issue, as in the past we might have been left with a collection of a few hundred photographs, some letters and maybe a few diaries and other possessions. Nowadays it is not uncommon for people to leave behind thousands of digital photos, tens of thousands of e-mails and countless status updates. Therefore questions of meaning are built into networks that contain both incredibly poignant moments and transient bits of information with no sense of order, hierarchy et al.

In 1945, Bush was already critical of the progression of science and its inability to provide scientists with better tools for handling the massive external records of

---

[32] Johnny Cash - *Ain't No Grave* [Official HD]. In 2010 over 250,000 people had contributed to this memorial: https://www.youtube.com/watch?v=WwNVlNt9iDk. [Accessed: 15th August 2016].
[33] Actor Network Theory - see glossary.

data they were creating. In his paper he laments "so much for the manipulation of ideas and their insertion into the record. Thus far we seem to be worse off than before – for we can enormously extend the record; yet even in its present bulk we can hardly consult it" (Bush, 1945: 12). Fifty-two years later *Data Smog* is published, in which David Shenk experientially evidences the same problem, data overload, which has expanded beyond our own comprehension – even with the inclusion of many of the labour saving technologies that Bush describes within his paper. It could be considered ironic that in 1945 Bush was already trying to escape the mass production and pressure to absorb data in his daily life and yet today his theories have become a model for mass accumulation and aggregation of data, for example within the field of 'lifelogging' (Sellen & Whittaker, 2010). The auto-saving of data within the systems we inhabit, such as social media, becomes a problem for the living. Although technology has greatly improved our systems for finding, cross-referencing and editing data, we have simultaneously constructed technologies which allow for greater production and publishing of data. This is particularly problematic when it comes to personal data. It is clear that through technology the problem has not been solved but has simply changed scale – the greater effectiveness of data aggregation has resulted in an exponential production of data. In this case, due to the proliferation of saving and reactivating data, notions of deletion become an anathema in contemporary society likened to concepts like censorship (Mayer-Schönberger, 2011).

This contemporary desire for saving everything is strongly linked to the digital medium that provides relatively cheap or free storage. It has collaboratively created digital hoarders but it has also propagated some forms of digital abstinence (p.128) as well as 'Death Switches' and other deletions rituals that aim to engineer the conceptual death of data. Eagleman (2009) in his book *Sum: Forty Tales from the Afterlife* playfully makes fun of this diversity in attitudes towards death, with one of the short stories focusing on the way that Death Switches have created a society where people pretend to not be dead at all, posing a problem for the living (p.67). A site like *mydeathspace.com*, an unsolicited collection of dead people's pages from *myspace.com*, creates an enforced community of the dead that situates their profiles outside social networks of the living. Predictions of when dead users on Facebook will outnumber the living[34] indicate emerging tensions between the living and the dead online. In this case we may ask how much agency can we extend to the

---

[34] An info graphic called *Digital Demise, What Happens To Your Online Presence When You Die?* calculates that in 2065 the dead on Facebook will outnumber the living: http://www.webpagefx.com/blog/wp-content/uploads/2014/06/Digital-Demise-Infographic.jpg. [Accessed: 11th September 2016]

dead? What is the role of the dead in contemporary society? And how can design begin to address some of these complex interactions that are being mediated through online systems?

Design for Death

Contemporary design methods are uniquely placed to contribute to the development of new rituals and practices around death and bereavement. As design has been opened up beyond the world of products and has begun to intervene and work within systems under labels such as service designer, experience designer and co-designer, the idea of "designing for a purpose" (Sanders and Stappers, 2008) that puts emotion and experience at the centre of the design is becoming an established goal for a range of companies and services. Latour (2008) also considers how design has shifted towards social impact. It has been opened up to new understandings that include the "very substance of production," it has been expanded "from the details of daily objects to cities, landscapes, nations, cultures, bodies, genes, and … nature itself" (Latour, 2008: 2). Latour discusses how design through this redefinition has the potential for turning objects into things by promoting them as matters of concern and that this form of expansion means that designers must take up issues of morality. As design moves beyond critiquing, observing, documenting it becomes a practice of critical action called redesigning (p.6) and situates itself within the realm of public engagement.

When Latour speaks about things as gatherings he opens up this theory of design as engagement, in which all things may be considered as social and inclusive. He lists the attributes of 'design as revolution' to be "modesty, care, precautions, skills, crafts, meanings, attention to details, careful conservations, redesign, artificiality, and ever shifting transitory fashions" (p.7). It is these characteristics of design that must be observed when engaging in design for death, including a consideration of whether these things (personal, archival, medical, funerary) need redesigning and how this will shift or alter current practices. The Design Council's May 2015 post *Reinventing death for the twenty-first century*[35] reflects this shift by detailing some of the challenges and ways that design could intervene within end of life care, both in terms of the appendages linked to dying at home but also in terms of new rituals, breaking taboos and the introduction of new technologies where appropriate. They additionally mention design competitions such as

---

[35] James Pallister (2015) *Reinventing death for the twenty-first century* http://www.designcouncil.org.uk/news-opinion/reinventing-death-twenty-first-century-0 [Accessed 10th August 2016]

Designboom's *Design for Death*[36] that have opened up this topic for discussion within the design community, and the *Death Café* movement[37], which started in 2011 and aims to give people a space to have open and honest conversations about what death means to them. IDEO, the social innovation company, has also run projects that aim to redesign the experience of death within the hospice sector[38] and have launched a challenge on their *openIDEO* platform for community participation in the question "How might we reimagine the end-of-life experience for ourselves and our loved ones?"[39]

Contemporary Legacies: Speculative Design and Research

In *The Future of Looking Back*, Banks (2011) considers some of the advantages and issues of having a legacy that includes digital data. He explores various ways in which data can be experienced and stored for future generations. He asserts that with good design our digital lives can be an opportunity for new and positive ways of engaging with and telling the stories of the dead. That by being creative with technology, bringing legacy into the home and considering the unique features of digitality, such as randomisation (surprise) and connection (sharing), people will have a different relationship to data. In this way people will have the opportunity to relate to different pieces of data over a longer period of time, rather then experiencing everything, thus having a much richer experience due to the mass of data available. Along with his own research on the *Technology Heirlooms Project*[40] Banks discusses how several technologies already in existence such as 3D printing, which can physically reproduce a copy of a digital object, and *PhotoSynth*, which is a tool that has the ability to digitally capture physical spaces, could contribute to the creation of personally memorable and sentimental digital/physical artefacts. These artefacts, once created, have the potential to blur the boundaries between digital and physical things and be passed on by loved ones as legacy.

Michele Gauler's (2006) speculative design project *Digital Remains* also uses the properties of digital systems to consider how data could respond to family networks as a form of legacy. Her *Access Key Urns* explore how data could be housed in these physical devices which locally store a persons digital presence but are also designed and materially produced to reflect that persons interests.

[36] *Design for Death* (2013) http://www.designboom.com/project/design-for-death-living/ [Accessed 10th August 2016]
[37] *Death Cafe* http://deathcafe.com/ [Accessed 10th August 2016]
[38] *Redesigning Death* (2015) https://www.ideo.com/work/redesigning-death [Accessed 11th September 2016]
[39] https://challenges.openideo.com/challenge/end-of-life/brief [Accessed 11th September 2016]
[40] A design perspective on three technology heirlooms. https://www.microsoft.com/en-us/research/publication/a-design-perspective-on-three-technology-heirlooms/ [Accessed 8th September 2016]

By merging physical and digital properties, it takes advantage of the distribution of digital legacy to allow each family member to have a copy. It is also a thing that can be physically placed within the home, allowing the dead to retain a sense of presence that is aesthetically fitting to our language and ritualisation of death. The urns are additionally linked together so that when one family member accesses the digital archive, the rest of the family can visibly see an interaction. This means that the dead agent is actually able to connect the family from beyond the grave, extending both their presence and role within the family network.

Figure 3: Michele Gauler, 2006, *Digital Remains Access Key Urns*, part of a collection of three speculative design products, which have been on display to the public: 2006 *Royal College of Art Degree Show*, London/ 2008 *Museum of Modern Art* 'Design and the Elastic Mind', New York/ 2013 *Northern Design Festival*, Newcastle upon Tyne/ 2016 *Future Fest* 'Love after Death'.

Moving beyond the digital, the agency of the dead has also been explored speculatively by Auger and Loizeau (2009) in *The Afterlife Battery*. This research speculates on what kind of afterlife an atheist can come to expect. It uses innovations around the extraction of energy from the decaying body through the creation of a microbial fuel cell to create a series of batteries that fictionally contain the energy of a body. By engraving people's names on these batteries and asking them what they would want to happen to their life energy after death, Auger and Loizeau play with the concept of gifting your extended agency in

functional and aesthetic ways to your family[41]. Or using the energy to enforce your own presence and desires on your executor. Some examples of how people chose to use their energy included to power a battery-operated megaphone to allow the deceased to heckle football players after death or to be placed inside a torch for family members to locate missing keys or objects[42]. By choosing what to do with your extended agency people are able to consider their relationship with people through things. What do they want to power, which thing, and for how long?

These examples of design research show how agency can be shifted between digital and physical things. It can be extended literally, as is the case of the batteries or can be embedded within devices that serve as connection points. By using the gallery predominately as a mode of public engagement, speculative design has the potential to reach wide audiences but need not conform to the functionality of designing products (Dunne and Raby, 2013). Speculative design situates a story of the future within a designed object, taking on the properties that people value in art (Keaney et al, 2007) in the sense that the works function to challenge and help people adjust to new technologies and modes of exploring issues such as how comfortable we are with thinking about what happens to our objects and data after death.

---

[41] This has also been considered communally in the *Future Cemetery* project by the *Centre for Death and Society* (CDAS) http://www.bath.ac.uk/research/news/2016/03/01/future-cemetery/. This was launched as a competition to re-imagine a future cemetery drawing on architectural and technological innovations. The winning entry was *Sylvan Constellation,* which envisions a "network of memorial vessels which would transform biomass into an elegant and perpetually renewing constellation of light which could illuminate pathways." [Accessed: 20th September 2016]
[42] Auger and Loizeau (2009) *Afterlife*: http://www.auger-loizeau.com/projects/afterlife [Accessed: 26th September 2016]

II.
COLLECTIONS, CURATION AND ARCHIVES IN THE DIGITAL AGE

Considering Things

This section extends further our previous engagement with physical and digital legacy. It considers whether aspects of immersion, enchantment, performance and materiality can aid in drawing digital and physical collections together. These encounters offer a plurality of narratives, experiences and aesthetics, which have the potential to give a wider scope for reflecting on a person's life and death. Additionally, it aims to contextualise how materials embody things and how things are framed through collections and archives. The term 'thing' has been selected over 'object' or 'stuff', due to the rich interdisciplinary discourse that has opened around it, giving things the ability to be protagonists in human relations. Things are able to slip beyond boundaries associated with the living and non-living, digital or physical, and even lay claim to agency or animacy in their ability to shift and develop the networks they co-habit (Latour, 2005; Ingold, 2013; Malafouris, 2013). By situating things as a bundle of connections within their networks, they are vitalised as producers of those networks. The deceased become a player in this network remaining present through their things. This affects the living in multiple ways: sometimes things are a haunting presence, at other times a comforting connection. This mirrors how the previous section considered the agency of the dead through the living, which was mediated via design, aesthetics and narrative.

Although this research works with things, it is not a philosophical discussion of the nature of things. The aim is not to study things but to construct a practice that engages with things[43]. The interdisciplinary literature used builds this practice by grappling with the role of things in relation to people. Therefore, although this research works with things, it does not analyse them. An ontological approach to thing theory[44] or the categorisation of collecting epistemologically is

---

[43] Miller (2008) attempts to use the term things generically in his book *The Comfort of Things*. He claims that this is due to the phenomenological baggage within this word, which privileges some kinds of things, such as bodies or houses over others. His construction of portraits through specific things also show how even the most mundane thing can construct the life of a person (p.290). Miller moves to the term 'stuff' in subsequent writings in order to avoid this categorisation (2010). This is also reflected in Turkle (2011) where she draws together objects and things to relate to an interdisciplinary telling of the meaning and emotion constructed through these objects. She also uses objects provocatively to "bring philosophy down to earth … to find common ground in everyday experience" (p.8).

[44] Thing theory is a philosophical branch, grown from Martin Heidegger's mediations on the entomology and categorisation of things as opposed to objects. By broadening things to explore them as an assembly or gathering they become relations. Heidegger distinguishes them from objects that he considers to be mechanically made, commercial and scientific. Whereas he values things as handmade, defining them closer to art and poetry. Latour (2004) moves beyond this dichotomy by complicating objects and enriching them as matters of concern (p.160). As does Brown (2004) in his chapter *Thing Theory* where he considers the role of

foregrounded in preference of an artistic process. By identifying how Hiller (1994) responds to Freud through exhibiting her work in his home [the *Freud Museum*], how Barthes (1981) finds his mother in a collection of old photographs and how De Waal (2010) traces his family's history through the Netsuke we locate the lenses that inform this practice.

By using the story of my grandma's thimble collection I also immerse myself in a personal experience of considering how making things digital can augment our relationship to existing collections. It allows me to position myself as a researcher within the research and take an ethical stance towards the practice by understanding it, as an aspect of my own legacy. Cross (2001) claims that designers do not develop knowledge through 'sciences of the artificial' but rather through their understanding of the artificial world, which allows them to add to and change it. It is this focus on techniques of the artificial, including how to construct people through things, that is developed through literature and stories.

The Legacy of Digital and Physical Things

Our engagement with the things we own or store is complex; we construct systems of value that can be very powerful, particularly when these things are entangled with specific people, memories (periods of our lives) or even ourselves. The loss of these things and longing of those lost can be highly emotional (Stewart, 1993). For most people the question of what to do with their possessions over time becomes a critical debate. This is due to the changing conditions of space, circumstances in family, break-ups, moving home, migration, war, trauma, death et al. The decision to keep a thing (particularly in circumstances of change when we are forced to edit down our personal collections) means that it is important to us. We have reflected on it and weighed up our own range of personal criteria and decided to keep it. This internal discussion is vital as it is our reaction to the possibility of giving up possessions which are precious to us that adds to the overall narrative of those things – the more often we think about them and assess their value the clearer we can see the value we place on them and understand why they are in our possession.

Death complicates this cycle of internal dialogue, as we become custodians of another person's things. Our critical criteria become blurred when we long to hold

---

objects when they stop working for us or are captured in photography or film. He asserts that in particular scenarios objects may prompt us to consider their thingness. We may also explore how these theories are developed by different modes of thinking through things and being through things (Moutu, 2007). In the book *Thinking Through Things* (Henare et al, 2007), the editors claim that they "want to propose a methodology where the 'things' themselves may dictate a plurality of ontologies. Where [Latour] presents us with a unifying revolutionist theory of things, [the editors of *Thinking Through Things*] advocate a methodology that might generate a multiplicity of theories" (p.7).

onto a part of that person's presence but cannot live surrounded by the past. Getting rid of these things is traumatic because they have been touched, held, sat on and lived with. They have become strong tangible presences in our lives and therefore are very difficult to let go of. For example, if someone dies leaving behind a chair that they always used to sit on we can do a number of things with it. If we decide to keep it, we can look at the chair and think of the person, we can use the chair and feel something of their presence. If we are not ready to deal with the chair we can put it in the attic and only take it out when we feel comfortable with it. The chair is not ambiguous, it remains, but the body of our loved one is absent. It can become a source of narrative, a way of introducing new people in the household to that person by saying "This is where they used to sit."

In contrast, digital things can be very ambiguous. They are typically distributed across a range of networks with different usernames and logins, legal frameworks and values associated to them. This makes it both difficult and very time consuming to gain access (Carroll and Romano, 2011). They are also often very large collections, which are difficult to separate into individual pieces. The systems that house our digital collections are also largely corporate (as stated in Ch.1, p.34). They work through someone else's database structure and logic for their organization and aesthetically do not necessarily speak about individual people (Garde-Hansen, 2009). In most social media there is no easy way to locate or search explicitly for specific moments and memories, making it both emotional and time consuming to reflect on their meaning.

However, digital things can also elevate our experiences of the dead through interacting with them rather then trying to unravel their logic. Digital things can be kept intact while still being separate and somehow parallel from our own lives. They can also be more collective, in the sense that you do not have to sell off the assets and divide possessions amongst family. Everybody can have a copy and access this parallel life and examine it as they wish (Banks, 2011). These affordances of digital things begin to unfold their value. Subsequently it becomes a question of how we use digital things, but also a question of how they are housed in material things. If material things hold our tactile experience of living, can we enhance these values by adding a digital element? If our digital collections grow too large how do we select or sort through this space, bearing in mind that many digital things are automatically saved within their systems (Mayer-Schönberger, 2011)? Is there any value in having an exact copy how they left it or is editing of vital importance here? If we do want edited collections of digital

things the editorial role becomes intrinsic to the narrative of that person. These theoretical dilemmas are addressed through the practice in Chapter's 4 and 5, which construct them as evolving dialogues within the co-design process.

How people continue to remember us may no longer solely be determined by the material possessions that have stayed with us throughout our lifetime but rather our digital 'afterlife' in the hands of the living community. As Daniel (2007) states, data may be considered as a mark or trace that needs to be interpreted whereas a "database is relational and non-hierarchical. It is a structure that persists while its content evolves and is displaced… all the possible meanings of stories, statements, images and words interact, and possibly conflict, to affect and change their future meanings" (p.7). This distinction shows how the framing of our collections through classification, materiality and interaction inform their aesthetic qualities. They also inform how people see and interpret us in the future, which will depend on an evolving digital archive that may continue to be manipulated after death.

Technological Things as Mediators

Technological things merge the digital and material, creating new understandings of our relationship to things in death. This includes the way that communication technology can enhance the agency of the dead (Grey, 2012; Walter, 2008). In *Passing on & putting to rest: understanding bereavement in the context of interactive technologies* Odom et. al, (2010) discuss how our relationships after death are mediated through technology. They tell the stories of their ethnographic fieldwork. One account talks about a mobile phone being buried with the deceased; it was buried as a means of communication, used functionally to pass information to the deceased, such as the football scores of their favourite team. The phone is used in a very similar way as people writing to their loved ones on social media (Brubaker and Hayes, 2011) and there is a tangibility in performing the act of communication through a device, computer or phone. By focusing on the device rather than analysing comments, Odom et. al, are able to chart the life of these technologies after death. They show how technology can be used in new and creative ways and that their functions are able to persist and in some cases provide agency. However, the researchers also found that inheriting technology can increase the sense of burden felt by the bereaved. For example, when inheriting a computer with all its files, this mass of data can leave a person

feeling torn between their perceived duty as a caretaker of the things and data and as an intruder in the privacy of the person who died[45].

Context is also important as one of Odem et. al's interviewees (2010) describes a rock collection inherited from his grandfather,

> "my Grandfather collected rocks. I never knew that. I didn't collect [rocks] with him ...but for some reason he wanted me to have it… What do you do with such a thing! ... I keep it under my bed for now." (p.1835)

This account shows the burden of inheriting unfiltered contents and collections. When the story is missing, what do we do with such an inheritance? This lack of understanding means that the person is stuck between owning a collection that has no meaning and getting rid of something that was important to his grandfather and that he had made the effort to bequeath to him. Without the narrative of shared practice these rocks are not able to extend agency of the dead. They do not promote care or interaction. They exist in the most minimal form, in storage. Questions about the legacy of things and how you share meaning are important as our collections grow. The shared stewardship that can be applied to digital things may help in the negotiation of meaning; someone may know the story, or complicate personal understandings through multiple contested accounts.

Massimi and Baecker (2010) have also weighed into this, engaging with what it means to inherit digital possessions after death. This includes the ways we use technology to remember the deceased and how this allows for personal reflection on our own digital estates. The authors state that the inclusion of technology into the things we inherit is not as straightforward as inheriting tangible items (such as clothes or jewellery). This is because practices surrounding the inheritance of data and digital assets are still developing and there are not the same social, cultural or religious guides as to how this should be approached or dealt with. This has led to divergent ad-hoc practices that constitute relationships with the dead. In their survey, Massimi and Baecker showed that a majority of people had never thought about how they wanted their own digital estate to be handled but at the same time were using their computer and the internet to help them remember, commemorate, or reminisce about their deceased family member.

---

[45] This has led to the development of activists, such as Vered (Rose) Shavit, author of *Digital Dust* blog (http://digital-era-death-eng.blogspot.co.uk/p/about.html) who assert that the organisation of online collections is of the utmost importance. Following her own experiences of inheriting a laptop full of content, she sets an agenda for working with technology providers, academics and legislators to help the public adapt to this form of legacy preparation.

This shows the need for developing a better understanding of what we should do with digital things. Massimi and Baecker question whether "despite the culturally prevalent "disposable technology" paradigm, and the idea that the data may matter more than the substrate it is stored on" (Massimi and Baecker, 2010: 5) we need to consider further how we interact and experience data which moves beyond our current technical systems and devices. However, when our experiences of digital things differ so much that some participants feel little or no reaction to the things themselves and others liken their inherited mobile phone or laptop to jewellery due to its presence on the body, we can begin to acknowledge the complex role that technological things will play in future.

The Intangible Inheritance

The story of my grandma's thimble collection interweaves with theories of things. By approaching her collection as a biographical narrative consisting of a Skype call every Saturday for a period of three weeks I start to put these theories into practice. During these calls we focused on telling the story of each of the 257 thimbles in her collection, including how they were acquired and what meaning they hold. This time between discussions allowed for reflection on the collection but also acted as a way of making time to talk to each other and having a concrete action to do together 'discussing the thimbles.' This also acted as a preparation for how I identify the role of narrative research (Gunaratnam & Oliviere, 2009) with my participants and the balance between narrating, making and curating. In addition to the narratives constructed through discussing the thimbles themselves, this engagement has also solidified the fact that I will inherit this collection and become its custodian[46].

The Materiality of Thimbles

The thimbles may seem uninteresting at first, mass produced things from another time that rarely fulfil their functional purpose anymore. Without the status of other fine ceramics or metal work, it is questionable what their value is and if such a value exists, where it lies. As objects they are often labelled as tasteless or Kitsch, but they are humble things that easily slide into the background of any home.

---

[46] It is important to note that this research and the subsequent future act of inheriting the collection has been framed through the use of technology, which has enabled this virtual gathering in order to discuss the physical collection. Therefore both the software (Skype) and hardware (internal microphones and cameras) are vital in discovering the meaning behind these things, as well as my 81-year-old grandma having the technical skills in order to complete this mediation. To break this down further, it may be said, that due to our physical distance from South Africa to the United Kingdom and myself being the only grandchild out of eight that had any interest in the collection, the thimbles needed exactly the right social and technological conditions in order to be secure of their continued existence and appreciation.

Even when collected they seem somehow small. However, with 257 thimbles, their presence is strong yet contained and manageable in their dowel framed containers. The collection is part of the background of a small flat in South Africa and is also part of an individual, an individual that is often enmeshed with her collection – "gran and her thimbles" say the family affectionately but also superficially. They do not understand. These little ceramic, glass and metal shells are made of more than their material, aesthetic or financial qualities. They are an embodiment of places, a collection of journeys (both spatial and temporal) and a collection of the self. They represent an externalised reflection of self in a very particular form, which differs from the photograph (Barthes, 1981) or written reflection (Foucault et al, 1988).

Figure 4: My Grandma, in Johannesburg, showing me on Skype one of the glass thimbles she acquired in Germany.

The very sameness of these things all sat side by side in their wooden display cases differs from the range of tourist findings one might bring back from France or Greece. They are able to be read as things and to trigger places in ways that are inaccessible to all but the collector so that she can scan across them: moving seamlessly from a small village in Australia that had an Elvis convention; to Germany that was brought back by one of her children but also contains her own memories of visiting Germany a long time ago prior to the start of the collection; to being a child and using the working thimble to do her embroidery with her mother at her side – both her and her mother's thimbles, now sitting side by side, just one more experience amid the collection.

Figure 5: Two of my Grandma's thimble trays in her home in South Africa.

She describes the fact that unlike the photograph, which captures a singular moment, for her these thimbles are active experiences. They contain periods of time that continue to gather with each new experience of the same place. This is enacted both through their materiality – for examples the English ones are mainly bone china whereas Cypriot ones tend to be enamel and silver (which is actually quite rare for thimbles) – and through their decoration, defining their singularity through the inscription of a single word of a very specific place, like a particular castle in France. Others are themed with identifying imagery such as rare Australian birds found in particular areas of the Western coast.

Finding the Meaning in the Collection

We can see when considering the materiality and status of the thimbles that it is easy, as a bystander, to overlook these things that make up the background or environment of a person's home but at the same time to unconsciously begin to think of the thing and person as synonymous. As mentioned above, gran and her thimbles become inseparable and create a new being. The new thing 'granandherthimbles' is different from the gran before the thimble collection. She traces the transformation back to the death of her husband. The collection is not

only part of her new identity as a widow but of her re-identification with her childhood through her own and her mother's working thimble. They transition and are translated from functional to decorative through the dowel frame. It would be a mistake to limit the exchange and excitement in the process of collecting and discussing the meaning of this collection by saying that, if my grandmother passed away, the role of the thimbles in my life would be to symbolise or signify my grandmother. This is to undervalue the thimbles themselves, to diminish them to the point of a virtual symbol, as something that is only standing in for something else that is no longer here. It does not take into account the agency of the things themselves and how their use within my environment would keep her presence in my life.

If we look to the work of Daniel Miller and his understanding of the way 'stuff' creates people[47], it would be truer to say that the thimbles are an extension of my grandma, as they hold her experiences and are used functionally as non-technological memory devices. Miller states

> "the problem with semiotics is that it makes the clothes into mere servants whose task it is to represent the Emperor – the human subject. Clothes do our bidding and represent us to the outside world" (Miller, 2010: 13).

This critique of the way that stuff is often classed as superficial, rather then constructive, is part of what Daniel Miller terms a 'depth ontology' in which we define a person's true nature to be deep within their body as opposed to on the surface. Yet what I am beginning to the see through listening deeply to my grandma, enthusiastically telling me and showing me (when she can get her iPad to face the right direction) the role the thimbles play in her life, is that these objects have an agency (Gell, 1998) that transforms them into matters of concern that need to be cared for (Latour, 2004; Latour, 2008). She does not need to prove why they matter or necessarily define what they mean, as long as we can use them. For me, they have a different function. They give me an entrance into many experiences that I would not have known how or why to ask about. A new narrative of my grandma's life emerges through the thimbles. This narrative does not reveal spectacular actions or events (like weddings or birthdays) but creates an overall picture of her through their collection.

---

[47] Miller develops this notion across two key books *Stuff* (2010) and *The Comfort of Things* (2008), the latter of the two is a collection of written portraits showing how people were constructed through interviewing them about the things they owned and how they played a role within their lives.

Miller (2010) supports this though his analysis of theories of representation. Representation does not reveal much about the actual relationship between people and things (p.48). Rather it is the frames we should be paying attention to that inform our expectation and contextualise our engagement with stuff. Goffman (1974), Gombrich (1979) and Miller (2010) develop theories of frames that help us understand the significant role that things play in our lives and place them on the same level as social engagement with people; I take this point up later in Chapter's 4 and 5 with my participants. This is further emphasised through questioning what we mean by materialism. Common beliefs surrounding materialism make us feel like we are not supposed to pay attention to the material, stuff, as it always comes at the expense of paying attention to the person (p.77). I would instead argue in favour of Miller's concept of stuff that by paying attention to the thimbles, taking on their meaning and offering to become their custodian, I am removing the precarity of their existence after death and the potential burden of inheriting them from the rest of the family (Odom et al, 2010). I am also acknowledging my grandma through appreciating the significance of these things.

The function of things is important to this theorisation, as it is through understanding their use that things come to matter. Montu (2007) asserts that "what is important is to collect and not to lose the relations that animate collections because such relations generate and structure the life of musical birds [flutes] as well as humans" (p.105), so through telling me the stories of the thimbles and the way they gather memories once they are positioned in their frames my grandma was teaching me how to use them and even offering a space for the collection to continue beyond her. By moving beyond a human-centric analysis of things as either semiotic devices or as a tool for mapping social relations, we can begin to break down the definition between subject and object; considering, as a designer, how thinking through things (Turkle, 2011; Henare et al 2007) could be practically worked with as a part of a crafting process (p.107), sensitively shifting as we encounter new layers and concepts.

Things have a role to play in instigating this research. They exist as frames for biography creation that persist after death creating new functions. The research question «what new co-curated artefacts could be evolved from things?» forms new follow-up questions such as «how could their function be extended if they are to be exhibited and what frames this exhibition for the bereaved?» So although human relations are key, by taking the stance that the dead have agency and this agency is mediated through their things this research looks at

humans as collections of relations and things. It is important to set this ground in order to appreciate how methodologically things can be summoned and pulled apart conceptually as mediators of the dead. By channelling their agency within the creative process they move beyond signifiers or memories and within the exhibition space are given the frame to speak publicly about the dead person to the viewer.

Can the Digital Augmentation of Things Enhance their Value?

If the agency of the dead is transmitted through a digital medium, what kind of agency does it create? What kind of relationship can we form with digital things? When we think about things that hold sentimentality, digital things are often undervalued or forgotten about. At the same time, we are increasingly living with blended collections of physical, digital and hybrid artefacts (Kirk and Sellen, 2008), which hold a wide range of meanings and sentimentalities. We may have special e-mails, digital photographs, music or artwork on our computers in addition to material artefacts that comprise a whole range of things. Recordings of people are also undoubtedly poignant and more pervasive through digital technology – the capturing of voice, countenance, movement – combined with the use of smaller devices with which events can be playfully captured as they unfold. In broad terms, the things we keep that become sentimental do so for a range of idiosyncratic reasons, which cannot be fully defined. But if materiality does play a role in the way we respond to things emotionally before we even see their contents, then I would argue that we must understand the properties of the digital as a material (McCullough, 1998; Lange-Berndt, 2015). Giaccardi and Karana (2016) have also expanded the discourse around making with digital content, presenting an approach to material experiences that incorporates digitality in sensorial, affective, interpretive and performative ways. They claim that "understanding material experience will pave the road to a new way of designing digital artifacts"[48] and that the material choice creates new forms of interaction.

Focusing once again on the example of the thimbles, it would be easy to think of them as fitting the criteria of sentimental things. They are small, made of a range of materials and have a strong link to the body. They talk of histories; both in terms of the things themselves protecting the fingers whilst sewing and darning,

---

[48] This quote is from Giaccardi and Karana's 2016 paper presentation of *Foundations of Materials Experience: An Approach for HCI* at 13:43 available at: https://www.youtube.com/watch?v=Slu9PHTHS6c [Accessed: 25th September 2016]

but also the history of my grandma's life. However despite this rationale, the thimbles do not conform. In fact they inspire quite the opposite reaction, in the sense that the family undoubtedly do not value them, due to their material and aesthetic qualities. As a designer I see the potential here for the thimbles to be digitally augmented; either via linking them together or by adding extra content about their stories, how they were acquired or where they come from on a virtual geographical map. This augmentation would create a new context to extend their presence across the family and even create links among those physically distant in a personal way. The fact that digital things can keep a person's legacy intact while still being separate and somehow parallel from our own lives is quite compelling. However, there are also questions of authenticity: do we place more value on an exact copy or on an edited collection of digital possessions? If we do wish to have an edited collection of digital possessions, important questions need to be raised such as: who takes over this editorial role when someone dies; who decides whether things are left or deleted, translated or preserved; and what impact does this have on the community (family or wider networks). Therefore, depending on the thing and the community using it, the addition of digital content or even full digitisation may actually have the potential to increase the meaning of the original and contextualise its place in people's life.

Jayne Wallace has explored the role of empathy, beauty (Wallace and Press, 2004) and enchantment (McCarthy et al, 2006) through digital jewellery (Wallace, 2007). Her work contextualises the role of crafts and aesthetics in relation to what she terms functionality and gadgets. It is the ability of the things she creates to engage with us emotionally that pushes them beyond the gadget and develops new approaches to crafting in the digital age. She argues that craft has always situated itself technologically. By opening up craft and making to the digital, we are able to create new experiences. That blends the characteristics of digital: temporality, interaction, sensory with handmade, sentimental or historical things. In this case the digital may add extra layers of immersion, new forms of functionality or re-contextualisation of known objects.

Figure 6: Wallace, J., (2010) "forget" digital locket, part of the *Unpicking the Digital* series. A series of four digital lockets exploring notions of memory, loss and our relationship to digital technologies.

The digital locket 'forget' (above) is a good example of this. By using the form of the locket people are able to understand its historical function and expect that hidden internally is a precious photograph. The digital locket extends this functionality by including an element of interaction, in which the photograph decays by a small amount every time it is opened until eventually fading away. The digital adds an unexpected interaction and communication between the human and the thing. By opening it, you affect it. This shifts the value of a singular digital photograph, as one must consider how accessing it often will make it decay. This restraint may make us memorise the photograph and context in more depth. It may also help us to question our relationship to the prevalence of digital photography. Nevertheless it is the locket as a casing and historical context of the thing that helps to create these questions and plays with the agency of the digital photo through Wallace's addition of material qualities such as decay.

Material qualities are of vital importance to a thing's perception, as found by Gulotta et al, (2013). Within their research, they tried three technological tools that provided different elements of archiving, fading or decay to explore digital photographs as legacy. The aim of this research was to use design probes to explore digital decay. Their participants however, responded critically to the concept of digital decay, claiming that it lacked authenticity to the digital medium and that essentially the photographs did not need to decay. The difference between the two pieces is that the locket merges conceptual and physical materials, which allow the digital to be seen in the context of physical things. The forget locket works by making the everyday slightly strange whereas the software

that decays your photos exists in the digital medium and its contexts are Photoshop filters. Therefore as the decay happens it feels manufactured and the participants respond to this.

Figure 7: Uriu, D., and Okude, N., (2010) *ThanatoFenestra: photographic family alter supporting a ritual to prey for the deceased.*

ThanatoFenestra (Uriu and Okude, 2010) is a digital memorial that uses the qualities of digitality to play with the traditional materials of a Buddhist home shrine. This minimal interaction causes the projected image of the deceased to flicker with the movement of the candle, thus causing the material and digital to communicate with each other. This sense of agency creates liveness and performativity in the thing and alludes to its spiritual nature in terms of communicating, through prayer with the dead. Moncur and Kirk (2014) also consider the material properties of digitality and a framework for identifying when memorials should be designed as physical, digital or hybrid objects. They develop this emergent framework through the identification of actors, inputs to be displayed, purpose of the memorial and the medium of the message e.g. personal, cultural, religious, secular et al. They identify the design opportunities and test their framework through the construction of a bespoke memorial called *Story Shell* (Moncur et al, 2015).
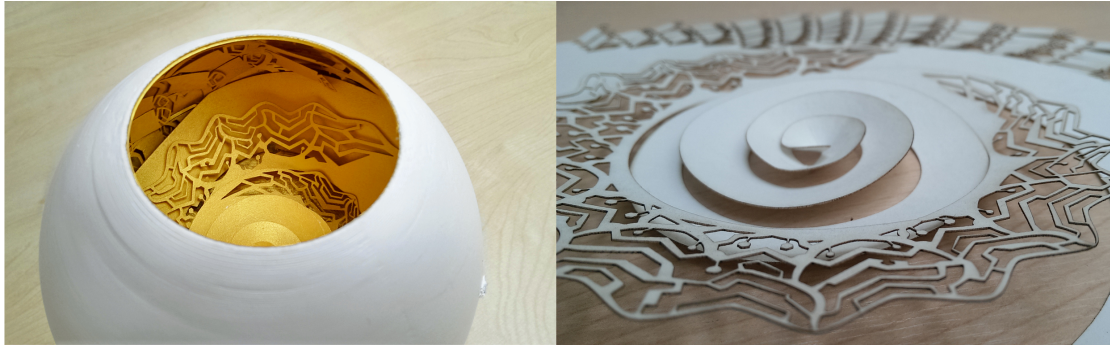
Figure 8: Moncur, W., Julius, M., Van Den Hoven, E and Kirk, D. (2015) *Story Shell: the participatory design of a bespoke digital memorial.* Photography: Miriam Julius.

This memorial device was designed to reflect the environment and symbols associated with a person's life. Unlike the previous two examples it is not an existing thing but contextually references a shell in terms of its form and function. Visual cues are used as a bespoke response to the stories and places that they visited with the bereaved mother, Mayra, as part of the research and the device was made specifically for her. The memorial contains audio stories that are activated through cupping it. There is a tactility evoked through sharing moments with this thing, which responds to you and constructs a listening space. There is also an exchange of agency at play with the *Story Shell*, in the sense that you feed it with stories and when you touch it you are able to hear them played back to you. The memorial device was constructed using a mix of 3D printing, laser cutting, hand sanding for smoothness and *Arduino* hardware and software.

Although the device does become an appropriate housing for the precious recorded stories, there is a question of the relevance of the material thing itself: how often and when should someone listen to these stories? As a memorial do they need to listen to them, or is it enough to simply know they are there? Unlike the *ThanatoFenestra* you must have a desire to listen to the stories in order to use the thing, and although it is bespoke it is not handmade. In terms of the interaction experience it is similar to a photo album – the participant is able to place things inside and access the contents. So does the materiality of this thing impact its continued value? The paper (Moncur et al, 2015: 6) identifies that it was the process that was most valuable to the participant; particularly poignant was the selection of stories to put in the shell and the time spent discussing her son's life with the researchers. The process of working in a participatory way reflects my own approach to working with the bereaved, alongside the deeper consideration of how people can work with researchers in a transparent way, that is beneficial to all involved. This will be reflected upon further in Chapter 4 as part

of creating new practices for design (p.104) and appropriate to my distinctive research contribution to this field of practice.

Figure 9: Odom, W., Banks, R., Kirk, D., Harper, R., Lindley, S. and Sellen, A., (2012) *Technology Heirlooms*, Socio-Digital Systems Group, Microsoft Research Labs.

Perhaps digital things can also take on the properties of physical things. By housing them in materials, such as wood or plastic, they can be spatialised within the home and separated from other digital content. This helps us to interact with them and think about them as singular, tangible and inheritable (Odem et al, 2012). These digital things include *Timecard* that stores a family's digital content by person and *Backup Box* that locally stores tweets visually and chronologically working through restructuring the digital content. They are not only presented as things and interfaces in aesthetically different ways but function as new experiences. This approach to structuring and ordering digital collections, as well as keeping them locally (rather than online), begins to hone some of the ways we can use hybrid things to re-contextualise and manage our growing collections and question their value.

Defining an Approach to Collections and Archives

While previous sections in this chapter have focused on developing the groundwork for our relationship to things as a category, this section begins to integrate lenses that frame an approach to making through collections and archives. These can then be used within design research. It further develops my approach to things, in relation to their collection, display and usage, and informs the way that I later consider how to co-curate and exhibit the artefacts made by

my participants (Ch.5, p.135). This approach to curation acts as an assemblage that constructs people and places. These lenses compare and reflect on: Carolyn Steedman's definition of the 'Archives' in relationship and in contrast to Jacques Derrida's; Roland Barthes' self-reflection on his collection of photographs; Sherry Turkle's discovery of her father in the 'Memory Closet'; and Edward De Waal's genealogy through the 'Vitrine of Netsuke'. The given literature constructs an approach to engaging with possessions that is informed by experience, memory and materiality – where materiality includes the consideration of digital data as a specific material of linguistic, sonic, pixel and temporal structures that can be crafted and enmeshed with physical materials.

Introducing Derrida's Approach to Archives

In *Archive Fever: A Freudian impression* (1996) Derrida considers the relationship between people, institutions, storage and meaning. The nature of the archives and the way that these archives have shaped society is of particular relevance. This includes the way that institutions create friction through their control of the mode in which archives are framed and stored. Derrida maps out the institutionalisation of the archive(s) through the friction between the words commencement (Greek 'arkhē') and the word commandment (Greek 'arkheion'), the laws that govern the usage of the archives. This responds to the way that politically we have been made, as a society and individuals, by the types of structures that allow and prohibit access to people and places from the past. It is through this tension that Derrida draws out his thesis building on the continually growing abrasion between the institutions of archiving e.g. museums, archaeologists, governmental bodies – we can now add to this list Facebook, Google, archive.org, the Library of Congress et al – and the materiality, geographic and topological location of 'artefacts' themselves e.g. in the home, underground, online (in data centres), on smart-phones, hard disks or other computers. Here we might consider the location or environment to include the shifting nomological frameworks that categorise digital things as legacy and emotions of the user inheriting these vast archives. By framing the archives through an institutional commandment an implicit value is connected to storage, as a concept. This has influenced the contemporary relationship to online storage, which has become known as digital archiving (Lyman and Kahle, 1998). The naming of digital collections as digital archives is important as it implies a philosophical notion of the archive onto digital systems (Garde-Hansen, 2009). So the first question we must address within this section is how much of the character of digital archives conforms to a philosophical understanding of the

archive? Personal digital archives have enabled people to hoard a more vast collection of personal paraphernalia than ever before. The ubiquitousness of these archives means that socially the living will be required more and more to collect and organise the archives of the deceased.

To expand on the institutional relationship to data, one may consider the nature of 'found artefacts' through an institution's commandment (for example that of the museum as mentioned above). Through the museums arkheion (commandment) artefacts will be exhumed, cleaned, taken back to the museum, preserved and potentially displayed and curated. The nature of the museum as an institution of education and research with a particular location and governmental funding demands that 'found artefacts' belong to the museum and thus should be disconnected from their origin and placed in a new museum narrative (of education, display, research, curiosity). This is at direct odds with the idea of the arkhē (commencement) of the archive as the institutional practices formed from a nomological hierarchy have removed the artefact from its context and origin, destroying, the essence of the archive through its translation.

How does this translation fare when considering the nature of digital possessions whose nomological grounding is constantly being shifted? One may consider how these artefacts change when passed through and influenced by: a singular person, a community of people, a company, or any combination of the above. This is further complicated when considering how digital artefacts may react to traditional systems of ownership, privacy, public space, curation and narrative. Furthermore it is not only the relation between the person archiving and the make-up of the archive itself (e.g. its technicity) that needs to be examined here, Derrida also considers the root reason of why we archive. He looks to human nature with all its compulsive, repetitive, and nostalgic desire for the archive including the irrepressible desire to return to the origin i.e the root of our memories and actions. It is this interpersonal relationship to the act (process) of archiving rather then the product produced that truly begins to develop the question of what kind of relationship we want to have with personal archives and how access and the structures or networks they exist within define these relations.

Derrida defines our relationship and nostalgia for the archives as simulacrums of living things (while they are living) and considers the way that this kind of archive creates an inheritance of translatable memory, whereby the memory of a loved one becomes translated by grief into a form of "erotic simulacrum" that allows for

the preservation of "lovely impressions" and forms our memories of death (Derrida, 1996:11). But by taking it to the personal, this romantic view of death and memory functions as a limitation of the archive. The personal archive is consigned to the role of reflection, which although translated remains a nostalgic impression of our loved one that has no agency of its own. Drawing again on Miller's (2010) argument that the way things are framed defines our social interaction through them, we can consider how the personal digital archives are additionally framed by an institution like Facebook. Taking the example of a Facebook profile asking you to reconnect with someone who is dead, the notion of agency is questioned. When a dead persons profile acts as a living profile it is acting within the coded framework of Facebook as a database but socially this is misplaced, as the dead should not be able to communicate with us. Therefore Facebook as an institutional archive for the living and the dead needed to alter its system of categorisation and define what interaction with the dead should look like. In 2010 this led to the memorial mode, which limited the features of dead accounts, it aimed to solve this problem of the dead having agency by defining them as dead. It is a very physical process though, as someone needs to report the death and in some cases may even be given a user control of the dead persons account to produce the actions needed for the account to become a memorial. This memorial however may also continue to be engaged with. By writing and sending messages to the dead, as an acceptable form of social interaction (Kasket, 2012). In conclusion digital archives, when constructed as assemblages of humans and non-humans, can have agency that pushes them beyond the simulacrum and positions them as a thing to interact with. By focusing on the structures rather than impression or preservation of the dead we can, in relation to Derrida, consider some of the tension created between the institution and the loved one trying to gain control[49].

Considering the role of stewardship from the perspective of an institution can also help to explore the agency of archives and how narratives can be explicitly controlled through human rather then coded curation. This is the case with the home and personal archives of Sigmund Freud. Derrida considers some of the tensions here, between the dead and the living, particularly through the reinterpretation of Freud's writings and his home. He considers the translation of the house of Freud – from the home (place where he worked and lived) to the

---

[49] An example of this being the famous case of the family of a U.S. marine, killed in Iraq, who repeatedly tried to gain access to his Yahoo e-mail account. Eventually the case had to go through the courts due to Yahoo's strict policy on protecting the privacy of the individual even after death. This sparked off a large media and Internet debate on the question of whether digital possessions fall under property law. One article covering the case: http://betanews.com/2004/12/22/yahoo-denies-e-mail-access-to-family-of-dead-marine/. [Accessed: 26th September 2016]

museum (where tourists come to learn about the life and work of Freud posthumously). Looking to the relationship between the words archive – arkheion – archon[50] Derrida states that the archives must have "a guardian and a localisation" and further considers that this altering of guardianship is what is occurring as Freud's house is translated from one institution to another (Derrida, 1996:2-3). Derrida then goes on to deconstruct these contrasting institutions, distinguishing between the archives Freud made and kept in his home and the home being translated into the museum which acts on a very different nomological platform with a new set of laws which demand the shifting of boundaries between the secret and non-secret, private and public, autobiography and biography. The curation of things within the house and the retranslation of the home through the curator's understanding of who Freud was and how 'they' wish him to be portrayed are two ways that the institution is attempting to create a controlled durable biography of Freud. But by shifting and augmenting the archive, the order that Freud had placed on his collection is no longer available. Furthermore we are not allowed to interact with these things, only to observe them and imagine how they played a role in his life.

Figure 10: *From the Freud Museum* (Hiller, 1994) is an installation commissioned by Book Works and the Freud Museum in London. It is typically exhibited as a collection of fifty archive boxes in a glass vitrine with their lids open. The Tate purchased it in 1999.

---

[50] Derrida (1996) defines the 'archons' as those who held and signified political power, representing the law within the 'arkheion,' the residence or institution of law making.

The meaning of these things is further augmented, as new things appear within this context and build contemporary associations, continuing in a live way to define Freud and place him more clearly within the context of history. Susan Hillier's work is also a good example of the way that things as a collection can intervene in a museum and play with the narratives already in place due to the institutional frames. Placing Hillier's art within the Freud Museum playfully pushes against the institution's commandment as the institution invites new interpretations of their collections. By working through a well chosen selection of things, placed in archaeological collection boxes, Hillier is able to gently participate in Freud's theories and his own collection of artefacts. The vintage cowgirl image and cow shaped creamer for example both speak to Hillier's understanding of sexuality and femininity as opposed to Freud's (Hillier, 1994: 44). She uses the presentation of these things to create dialogues with Freud's things through the medium of the viewer. Hillier describes (p.41-48) how her curation was affected by the vitrine in the room and that her decision to use it placed her art within a museum context. This incited the viewer to take each piece seriously, analysing it carefully as they scan across the vitrine taking into account the detail of each of the works. She describes how this is what we are trained to do within museums as we approach the works as a mode of understanding about the past, but not necessarily within art galleries. These curatorial dilemmas are further interrogated in Chapter 3 (p.82) where the role of the gallery in relation to ethics is framed through the hospice as an institution and in Chapter 5 (p.143) as participants grapple with the gallery as a space that constructs a specific notion of aesthetics.

Questioning Derrida's Archives Through Steedman

Carolyn Steedman's definition and interrogation of the nature of archives in *Dust: The Archive and Cultural History* (2002) questions Derrida's association between memory, nostalgia and archiving, by considering the role the archives play as a place unto themselves. Steedman begins by considering the relationship between the archives and the historian's body. Their dedication and devotion to the production and re-construction of history is performed by sifting through hundreds of documents to find something useful. The historian shows his dedication by travelling to a distant place to find the right archive, sleeping in an unknown hotel room, sitting for hours in the cold archives and pouring over records, trying to find the clue that will allow them to write the next historical text. The archivist and the archives create their own shared space of meaning – it is not a place for everyone and not everyone can access it. Through this

viewpoint Steedman considers and playfully critiques Derrida's fascination and idealistic concept of the archives as memory. She states:

> "It is a common desire – it has been so since at least the end of the nineteenth century – to use the Archive as a metaphor or analogy, when memory is discussed. But the problem in using Derrida discussing Freud in order to discuss archives, is that an archive is not very much like human memory, and is not at all like the unconscious mind… But in actual archives, though the bundles may be mountainous there isn't in fact very much there. " (Steedman, 2002: 68)

This is a very relevant statement for our contemporary understanding of archives as it is this analogy of memory that contributes to much of the claimed desire for a perfect record that is presumed to be achieved through digital archiving and particularly instantaneous saving techniques such as lifelogging (Bell and Gemmell, 2009). Less attention is paid to the organisation or what the usage of such records would mean to us (Sellen and Whittaker, 2010). Steedman states that, despite the size of our archives it is in fact the human voice forming the narrative from a range of sources that creates any structure or gives order to this mass. This implies that beyond the commandment and commencement of the archive is the embodiment of information into stories from the past. She considers the phrase 'Archive Fever' to push the notion of personal embodiment even further. Steedman describes the actual fever contracted by archivists who breathed in the dust of old books that in their decay produced air-borne meningitis. She claims, in jest, that there may even be considered a physical exchange in vitality between the historian and their ability to breathe life into history. An exchange of agency between the human and the archive.

Stories can be pieced together through records to tell rich narratives about hidden figures of the past (particularly women). It is in these enforced narrations within the magistrates that we hear about the others in history. There is a tension in telling these stories, as the voice is given after death through an institution of record. It provides a very specific way of telling, which needs to be creatively translated if these stories are to be given justice. There is a lesson here too for our contemporary assumptions around the 'autobiographical turn' and the enforced records that extend to digital institutions such as Facebook or Google that claim to give the individual a platform for communication.

> "There exists and has existed an urge to tell the self, and that it comes from within is of very little help in hearing these eighteenth-century cases of enforced narration" (Steedman, 2002: 55)

Although there is a desire to tell stories online there is also an increasing self-censorship (Mayer-Schönberger, 2011) that reveals some of the tension in using the online archive as memory. It is an increasingly observed platform whose aesthetic and structural frames influence what people choose to say and how they choose to say it (Garde-Hansen, 2009). It may be just as challenging and contestable to tell the story of a person online as it is in the archive, as you attempt to construct a narrative from a range of sources – defining an order, hierarchy and understanding of the way that person used that specific network. It is important to remember Steedman's assertion that the archive is nothing like memory; that the database, algorithm, order, interface, bureaucracy, framing, social policing and performing of our own body when accessing these 'things' must all be considered if we want to form a deeper understanding of the way we may interact and find meaning in our growing hybrid collections of digital and physical legacies. Considering Steedman's approach to the way that people sift through physical archives to create stories and Derrida's definition of the archives through our institutional and personal engagement with them. This research reflects some of the issues we encounter in our impulse towards collecting and what is needed to understand these collections. This is developed through the meaning of limited collections, where things gain significance through scarcity and thus warrant deep consideration.

Considering the Meaning of Less with Turkle's Memory Closet

In *Evocative Objects: Things We Think With* (2011) Sherry Turkle introduces the edited volume by describing her personal relationship to what she calls the 'Memory Closet' (p.3–10). Turkle describes it as a space that she could freely explore as a child. It was a space that felt like it had infinite dimensions and depth due to the vast collection of all the family keepsakes. She considers how although she had free access to the closet (a physical container of family possessions) it had been sorted through and sanitised before she got there and that the thing she was subconsciously looking for, her missing father, was not to be found. There was one exception to this, a photo of a man with his face cut out. A photo that, despite its incompleteness, contained important details about how her farther presented himself; his hands, posture, how he tied his shoes and even the tweed of his pants. The photo without a face became a thing of important

study, helping to fill the gaps of personal biography. Turkle presents the closet as a thing that was full of mysteries and clues to be uncovered and found, a kind of psychological bricolage in the mode of anthropologist Claude Levi-Strauss being used as "a way of combining and recombining a closed set of materials to come up with new ideas" (Turkle, 2011: 4). This description evokes the experience of searching for an important image, memory or comment on someone's Facebook page; or the excitement of Googling a person you know well, not knowing what you will find, what the algorithm will bring up and in which order; or the discomfort when a well known website is replaced by a 404[51], never to be accessed again.

On the 11th November 2011 at the 4th *Digital Death Day*[52], Tropenmuseum, Amsterdam, I was told the story of a girl whose family was trying to decide what to do with a memorial on Hyves. The Dutch social media platform Hyves (along with many other local social media platforms) was also dismantled as people moved their profiles to Facebook[53]. As they assessed the options it was obvious that the memorial was important to them and the choices they needed to make about this person's post-life were all critically considered. Do they keep the memorial active, as members leave, until the network shuts down and let it be lost with it? Do they move the memorial to Facebook, a place she had never known or existed on but that her network is now active in? Or do they archive it and keep a copy even though all interactivity will be removed and only the trace of the memorial will remain? Turkle's memory closet met the same fate as the Hyves profile. It was dismantled when the family moved, and many of her constructed stories, ideas and things she thought with were lost. Turkle describes her sadness at the time of losing these cherished objects of childhood but makes the statement that it was the loss of these things that caused her to reflect on how she combined them and how they made her think. There is something about the one image of her father missing his face that allows a certain playfulness of thought to emerge. The ambiguity of the image allows for creativity to step in and animate the photograph. One may question how this would have shifted if the photograph had been whole or if there was a large collection of photographs to explore. Would she have been able to get to know her farther better if the collection was larger? Or does the singular image inspire a different form of examination towards the collection? This playfulness is something to consider

---

[51] 404 is a HTTP error code that indicates that a website or a resource does not exist.
[52] See Context of Research p.12 for more information on Digital Death Day's.
[53] *Dutch social network Hyves sold to media group, as European-based networks feel the Facebook heat.* Mike Butcher, Nov 1st 2010. https://techcrunch.com/2010/11/01/dutch-social-network-hyves-sold-to-media-group-as-european-based-feel-the-facebook-heat/. [Accessed: 28th September 2016]

when thinking about the way that Google and Facebook archive, promote and display their content. Within this arrangement the user is largely powerless and their ability to explore, search and build personal narratives – to think through the data – is limited to the experience of using these services.

Looking to Barthes' Photographic Collection for a Tacit Approach

Building on Turkle's memory closet I move to consider Roland Barthes' description of his collection of photographs in *Camera Lucida: Reflections on Photography* (1981). Roland Barthes does not reflect on the qualities of a photographic archive except through chance discovery of details from the past through his analysis of old photographs; instead he attempts to emotionally understand the photograph and the practice or process of photography. Barthes unveils his exploration through a description of his own in-depth autobiographical experiences and his own reactions to particular photographs. His personable tone cuts to the heart of the personal archive, viewing it as a space to consider how gesture, frame and punctum (among others) instill different levels of meaning and emotion into various photographs. This becomes particularly poignant when Barthes begins to consider the archive of photos left behind by his dead mother. He describes the feeling of finding his mother who had recently died, in an image, in a box of photographs he was sorting. In contrast to Turkle's active (if unaware) search for her missing father in the 'Memory Closet', Barthes claims that although he "would have recognised her among thousands of other women" (p. 66) he did not find her in his collection of photographs.

Through this statement Bathes seems to illustrate that although there were many images of her, in various locations and styles of clothing, something about her essence was missing. The collection did not work in individual photographs but through a collection of fragments and glimpses that Barthes could interpret and animate through his active imagining. He considers whether any of the photographs could really 'capture' her. Barthes asserts that the only way he could catch a glimpse of 'her' in an entire archive of her photographs was through the act of imagination. This is similar to Turkle's use of the photograph as a tool for thinking. It is interesting to note that the one photograph that truly animates Barthes in which he 'finds' his mother is one of her as a child (Barthes, 1981: 67). It is through this specific image that he shows that it is not his own memory of his mother that animates him but the fragment of her countenance as a child through which he is transported to her. For Barthes, it is not the direct and exact recording, capturing or re-animating of his mother that allowed her memory to

live on but his own ability to engage with the collection of photographs and emotionally reflect on its contents.

> "I wanted to explore [photography] not as a question (a theme) but as a wound: I see, I feel, hence I notice, I observe, and I think" (Barthes, 1981: 21).

The question remains however for every individual to reflect on, when reminiscing in the digital age: how do you find the digital thing that speaks to you, the thing that continues to teach you about the person? There are a few points to be raised here concerning the potential of collections of digital and physical things. One is that when we consider Barthes' mother, hidden within the collection of photography, she is only revealed through a particular framing of subject. The punctum is expressed through the image and countenance of her form as Barthes goes to great length to show these elements combined can create a powerful sense of experience and immersion, perhaps more animating than an entire collection of photographs. Or even a video that captures more but focuses less. In the video recording we are immersed but is it a good thing for thinking with?

Barthes' body may also play a role through the sorting. The very act of moving image after image through his hands is enough to occupy the brain and provide a strong meditative space for reflection. The materiality of the photographs, as small handheld things, might provide the right forum for Barthes to think through them, capturing his mother. By delving into these experiences of archives, collections – the lost and the found – I begin to form a basis for thinking in design terms about the relationship we can have with people through things. This helps to build an approach to making that considers how much of the archive should be shown or edited, what role the body has in the production of the artefacts and how the collaborations may support moments of animation that can be built into the final pieces. Chapter 5 (p.131) shows how making is interwoven with experiences of people and things through loss, which are able to be co-constructed as embodied experiences for the participants.

Adding the Personal and Performative through De Waal's Netsuke

It is the exploration of the collection as a wound that moves me to examine Edward De Waal's 'Vitrine of Netsuke', which could be considered as the main character in *The Hare with the Amber Eyes* (2010). It is essentially the story of a

collection of netsuke[54] that covers their passage through time as seen through Edward De Waal's search and assembly of his family's lost history in the archives of Paris and Vienna. The netsuke travel through history and are rescued by Anna, his Great Grandmother Emmy's lady maid. Due to their size and connection to the children Anna saves them while the rest of the family possessions are confiscated, destroyed or sold during the Second World War. Through the Netsuke and the archives, De Waal is able to tell an accurate account of his family's history that revels in details. Details about the art of their world, the spaces and locations they inhabited and the different kinds of relationships they formed to the netsuke – from initial acquisition, to gifting, displaying, sharing, narrating and playing with them. Through the clear focus on this inherited collection of Japanese things he attempts to avoid nostalgia when talking about his own Jewish family history and their personal tragedies within the Holocaust. The family is explored through these things, which only tangentially coincide with historical events. This allows De Waal, as a ceramicist, to explore new materialities for thinking through his personal history. By understanding the Netsuke, he builds a connection to people he has never met before and the things become embodied with their presence.

De Waal explores this wound, this loss of history and family possessions by caring for the netsuke. He experiences a similar sense of embodiment to Barthes handling his mother's photographs, particularly when he takes one of the netsuke on the journey with him through the archives. He keeps it in his pocket and rolls his fingers around it while he is thinking. The netsuke are so intricate that they are able to describe themselves through feeling, and the repetition of this feeling expands De Waal's experience of his families history. They are things after all that have gathered stories and they are things that generate stories. They make De Waal ponder his great grandmother Emmy's connection with the netsuke, even though she died before he was born. He talks to his great grandmother through the things, asking what she thought of the netsuke, as she has not collected them herself. He questions what their value was to her if she did not add to them, but then considers what he has uncovered of Emmy in the archives. He concludes that she "loved stories, and the Netsuke are small, quick, ivory stories" (p. 174). This statement builds his personal biography of who Emmy was and how her use of the collection mirrors his own.

---

[54] Netsuke (pronounced "nets-keh") are small Japanese things that were used to construct pockets connected to the sash of kimonos. They are a kind of sculptural fascinator that secures the pocket like a button. Kataborinetsuke or "sculpture netsuke" would define most of De Waal's collection. They are intricately carved animals, people or naturally found things made predominantly of ivory or wood. For more information see the International Netsuke Society: http://www.netsuke.org/ [Accessed: 29th September 2016]

The vitrine that holds the collection of netsuke, is also of vital importance in their usage. The Netsuke's particular framing through the vitrine changes as various different family members are given ownership of the collection. The collection started in fashionable Paris with Charles who was the original collector of the netsuke. In his possession they are all lined up on green velvet shelves nestled within their vitrine. The vitrine in this case is used for showcasing his treasures in a form that adds to their uniqueness and presence, where they could not get lost or dusty. It is here that they can be appropriately cared for by adding a small cup of water to keep the atmosphere moist so the ivory does not crack. For Charles they are beautiful and rare things, expensive artefacts of Japonism. As they pass from Charles to Emmy their meaning changes. They move from public display to Emmy's private dressing room, in which, upon the turn of the little key, they open up as an interactive performance. They become "part of the children's world of things. This world is made of things they can touch and things they cannot touch." (p. 176) These small things, which they could occasionally access, would incite imagination, categorisation (all of the rats; largest to smallest) and create a momentary shared space for child and mother. One of the children, Iggy, became the owner prior to De Waal. They lived until his death in his home in Japan – the collection had returned to their cultural home. But beyond this they created a strong tangible link between the De Waal's and Japan. In Iggy's home they were both displayed and the vitrine opened up when guests were around. Here they could be passed around to hold and examine, the things were used for inspiring conversation and appreciation. Upon Iggy's death they were inherited by De Waal who was inspired through loss and custodianship to narrate this journey. Using De Waal's rich description of how things translate through inheritance and how this affects people's experience of them is picked up again as practice in chapter 4 (p.116-127).

When it comes to Anna, the woman who saved the netsuke, there is no trace, not even a last name to secure her place in history. De Waal's own journey is only possible because, although he inherited very little, his "gilded family" (p.282) left traces in the ledgers of dealers and dressmaker, in the books of Proust[55], in the newspapers and writings that have all been carefully preserved. So history is not fair; I think back to Steedman's enforced narratives of the magistrates and of who gets to tell their story and how these stories are told, because the telling matters. The Nazi's attempted to cleanse the traces of De Waal's family after they

---

[55]Marcel Proust, was a French novelist, critic, and essayist. Charles Ephrussi, the first owner of the netsuke, was one of the inspirations for the figure of Swann in Marcel Proust's *À la recherche du temps perdu* (In Search of Lost Time; titled Remembrance of Things Past in the first translation), one of his best known works.

had fled by renaming the buildings associated with them, the Palais Ephrussi on the Ringstraße, the bank Ephrussi, through an enforced buy-out. Perhaps most painfully with a symbol in the ledgers, a red stamp with the name 'Israel' for every Jewish man to unify their identity and remove all individualism (p.259). But erasure of memory is harder to enact then they thought, especially when traces are distributed and hidden in the archives across many physical locations. The archives structure a specific approach to preservation, but who holds the archives and how they are constructed is not politically free (Steadman, 2002). As we all push to document ourselves online, questions of censorship, abstinence and performance become key (Mayer-Schönberger, 2011) and it is still the telling that matters. It is this telling that will inform my approach to practice in Chapter 4 (p.116) where listening, distilling and the materiality of telling become modes of thinking and making through things.

De Waal reflects on his grandmother Elisabeth burning the "hundreds of letters and notes she had received from her poetic grandmother Evelina" (p.347). Choice and ownership make a difference here. This is not an enforced erasure. By burning the letters Elisabeth makes sure that her archives do not become an enforced telling of the past. Letting these things burn makes De Waal question his own archival impulses. He considers "why keep things, archive your intimacies? Why not let thirty years of shared conversations go spiraling in ash" (p.347). I reminisce on Derrida's musings of Freud where he asks the reader why he should "detain [them] with these worn-out stories? Why this wasted time? Why archive this?" (Derrida, 1996: 9) These two positions on what it means to bring a story into the world (Derrida, 1996) and what it means to destroy a collection (De Waal, 2010) are provocations for the digital age where many of these positions need to be rethought within the digital medium.

Mayer-Schönberger (2011; as discussed previously in Ch.1, p.34) suggests in his book *Delete: The Virtue of Forgetting in the Digital Age* that we no longer value forgetting and that as humans we must reclaim this important way of reaffirming ourselves within the present. In chapter 5 (p.128–168) he discusses a range of different approaches to dismantling the structure of digital archives. By provoking a series of adjustments to individuals, laws and technology, he seeks to destabilise current information power and addresses issues with cognition, decision-making and time in such large digital collections. To deal with the nuances of these digital collections, he states that "creative approaches may be the most valuable" (p.168) in tackling what they mean to us. De Waal talks about this cultural shift stating that he is in "the wrong century to burn things… the

wrong generation to let it go" (p.348). But if we are not going to let it go, then what should we do with it? What kinds of telling does it inspire, what new kinds of erasure? Perhaps this has something to do with our desire to keep the dead present, to continue those bonds (Ch.1, p.27), which is particularly prevalent in the digital age. We may glance towards Katherine Hayles (1999) and her material approach to reconfiguring the human subject. By shifting our gaze from presence/absence to pattern/randomness (p.285) we may focus on randomness as the "creative ground from which pattern can emerge" (p.286). It is the creative evolution that we will pick up on in Chapter 4 when considering the way that the archive emerges out of a design process.

Lenses for Designing with Collections

The encounters with things, collections and archives helps to frame this lens of literature vignettes, as they inform new ways of approaching practice: Derrida's framing of the archives through the **structure** of institutions; Steedman's **embodiment** of the archives through people's engagement in finding and narrating history; Turkle's use of a photo with a missing face to **construct** a more complete personal biography; Barthes **animation** when finding the image of his deceased mother that spoke to him in a large collection of photographs; De Waal's netsuke in their vitrine that become physical **containers** for family history. The uses of lenses as an analogy here refers to the fact that lenses can be used to focus in on details, to examine but also to draw out and see an overall picture with sharpness and clarity. This action of looking through lenses draw us into nuanced dialogues (Ch.4, p.117; Ch.5, p.131) and simultaneously provides the practice with an overview of the systems that things exist in and their meaning. In combination such qualities develop a crafted approach to the people we love, investigating the nature of personal archives and collections, including how we narrate and edit these collections to give them meaning.

This investigation goes beyond a 'shoebox' or edited collection[56] and instead uses the qualities of collections, archives and things. It creates a material expression of a person through the bereaved. These lenses shift the meaning of a durable biography (Ch.1, p.27) and use practice research to translate the meaning behind collections. There is no structure to what people find meaningful and this research does not intend to give any. Instead, it does develop ways of highlighting the

---

[56] In *Mediated Memories in the Digital Age*, Dijck (2007) mentions a range of research projects which focus on digital memory from the perspective of a digital shoebox. She critics this form of collection online as it seems to miss the affective qualities of memory becoming a simple storage technique p148 - 164: Dijck, José Van. *Mediated Memories in the Digital Age*. Stanford, CA: Stanford University Press, 2007.

importance of things and modes for thinking through things as a way of understanding the meaning that was already there, as opposed to constructing meaning when it is absent. Although the lenses are predominantly drawn from physical archives, collections and things, they can be used to refocus our understanding of the digital, whose affordances can provide new structures and containers for embodying the dead.

These frames also unearth a range of ethical dilemmas within this research. By exploring what is left behind through the wound, as Barthes calls it, the nature of such an investigation must be deeply considered, making sure that the practice is sensitive to those involved. It must also be understood that, by engaging with institutions, the research is cast within a specific nomological structure that will command the research to take on a certain form and to deal with data in a particular way (Ch.3, p.80). To subvert the institutional commandment of protection, anonymity and rigidity – in favour of collaboration, ownership and flexibility – will put this research in dialogue with notions of design as a situated action (Simonsen, 2014). It engages through specific communities with the aim of levelling interaction and power relations (Bradwell and Marr, 2008). Ethics has gained a greater significance more generally within the arts and humanities, as the emphasis on working with different publics in non-traditional art and design settings e.g. council estates (Jones, 2014) becomes a mode of exploring the contemporary role of these practices as they are translated across a range of sites. In the next chapter I examine the complexity of ethics and integrity in my own research as I unveil the process of working through ethics, research governance and recruitment with The Hospice of St Francis.

III.
ETHICS, CLINICAL SUPERVISION AND CREATIVE FRICTION

The research collaboration with The Hospice of St Francis (shorthand: St Francis) was initiated in 2012 after meeting the former director of The Hospice of St Francis, at the *Dying in the Digital Age* conference[57] in Bath. The project was granted ethics approval from both The Hospice of St Francis as a research site and Goldsmiths, University of London, in 2013 (see App.2, p.172–199 for full details) and the first recruitment cycle began in September 2014. This research will reach completion in February 2017 with a month long exhibition of co-designed artefacts being shown at the *Stephen Lawrence Gallery*, University of Greenwich[58].

Creative Friction and Building Trust

One of the hidden labours involved in collaborative design and working on-site is developing relationships to partners and understanding the form a creative collaboration must take. This includes a negotiation about the way that ethics and integrity underpin this process. It is particularly challenging for practice research, when the result and experience of participation cannot be fully preempted. Getting the language right for all partners becomes an activity in itself where "dialogue is a living manifestation of the values of care and tolerance between the arts and humanities and the sciences" (Jefferies, 2012: 81). This includes remembering when to shift gear when discussing the work with researchers, St Francis staff, participants, art therapists et al. It was a steep learning curve. I remember poignantly, making the mental error of calling my participants 'clients' in an academic setting, the word had seeped into my consciousness from multiple meetings with the hospice and art therapists. Seeing the shocked and angered faces of my colleagues, as the corporate associations of the word made themselves felt, helped settle the boundaries of interdisciplinarity. Having said this, it is crucial in partnerships to show an understanding of the other's discipline, position and responsibilities. Being able to speak the language and terminology is a first step towards this and shows your commitment to the site. However, it is the intuitive way of talking about my research through narratives that always seems to inspire the keenest response, as this form of social

---

[57] For further information on this conference see: *Dying in the Digital Age* - CDAS hosts successful annual conference, 19th June 2012, http://www.bath.ac.uk/sps/news/news_0033.html [Accessed: 29th September 2016]
[58] For further information on the *Stephen Lawrence Gallery*: http://www.greenwichunigalleries.co.uk/ [Accessed: 29th September 2016]

description has the ability to transcend disciplinary boundaries (Gunaratnam, 2007).

This co-design research was explored with the hospice as a process in which a creative practitioner (art therapist) was teamed with a participant, who had been through bereavement and wanted to explore what was left behind through making. The aim of working with art therapists was that they would have a background in personal artistic practice in addition to the knowledge of how to work with people in vulnerable situations. As part of the research governance, it was necessary to recruit and go through the process of background checking (DBS; App.2, p.183) before beginning recruitment through The Hospice of St Francis. This meant that by the time the recruitment cycle finished in early 2015 I had only one art therapist left who was able to commit to the project as a practitioner. Although the project shrunk in size, this allowed me to work with two participants and the art therapist to work with a third, which gave me a unique vantage point for comparing the process. In addition to this one of the participants I am working with is herself an art therapist. This allowed for reflection on how this research could impact the art therapy community and the meaning of making in relation to bereavement.

Working with a research partner like The Hospice of St Francis requires an understanding of the site and its day-to-day operations. As a hospice, this includes the fact that your research is an extra activity that has been added onto people's workloads. At times this is likely to be ignored or forgotten simply due to the flows of work involved in running a hospice service. It takes time to establish relationships and understanding, especially if there is no previous relationship in place. This is particularly challenging when the site is physically distant and when the time spent on site is precious and must be spent productively. Another challenge is the place of research within such context and how the hospice feels about practice research being undertaken throughout the research process, especially when this is undertaken over an extensive period. It is inevitable that during a four year period members of the initial team might move on to other institutions and roles.

Developing Understanding

From first meeting with the team from The Hospice of St Francis at the *Dying in a Digital Age* conference in Bath I was immediately drawn to them. After my presentation they approached me and asked if I had found a site for my research. They seemed to share an understanding of the importance of both creativity and

the digital within end of life care. On my first trip to St Francis the hospice too impressed, a light filled building in leafy green surroundings with artwork on the walls and bright colours that felt welcoming. Instinctively it seemed like the right site for this research, that we shared an understanding of what we were trying to achieve. Additionally the Hospice of St Francis was already working with Victoria Moore and Morag Cormack to trial their phone application *Legacy Organiser* "which lets users record how they would like to be remembered and to plan ahead for their funeral and farewell"[59]. I was interested in working with a hospice specifically as a site for this research, as notions of communication and care in hospices have been significantly influenced by digital death. This can be seen through an increased number of patients writing blogs, using social media support groups or simply expressing themselves online (Taubert et al, 2014).

I wanted to understand whether an increased focus on the creativity of continuing bonds could provide new modes of engaging with art and design within this environment. Also it was clear that the research could have a stronger impact if I was able to understand the networks that work closely with bereavement and the current role of the arts within them. By taking a situated approach to design, the hospice offered a site which contextualised this practice research and puts it to use through the collaboration. Additionally, there was a clear benefit to using the experience of the hospice team to help me develop my own practical understanding of bereavement and to consider in more depth how to construct an ethical practice for my research. It also provided a safety net for recruitment, as the hospice would be aware of the history of anyone that wanted to participate.

As the research progressed though issues began to form and the gaps in understanding produced a lack of clarity in the hospice's perception of their role within the research. To reignite the partnership and show my understanding of the site, I set out to more clearly define the hospice as a stakeholder in this partnership, by identifying three main advantages to hosting the research: training, publicity and research.

Training: as the research identifies new approaches to the use of making as part of a creative exploration of loss, it will add to the knowledge that the St Francis bereavement team has in relation to their use of art therapy and art practice in death and dying. Training may also be provided in relation to the subject knowledge of the researcher on digital death and how to help clients who are

---

[59] Groundbreaking Legacy app boosts staff-patient communication (2014) http://www.dyingmatters.org/blog/LegacyOrganiser [Acessed: 28th October 2016]

unsure what to do with the mass of digital things that they have inherited to understand the scope of services available.

Publicity: As I have got to know this hospice in greater depth I believe that one of it's core values is giving people artistic spaces to be reflective in; from the Zen garden to the range of forest walks and story chair to the art within the building and even the building itself. Every detail has been considered in order that the hospice feels in no way clinical but instead an inspiring space in which one can consider their life or the life of their loved one. I believe that this research, through the exhibition of artefacts produced would help reinforce this narrative to a wider audience and provide a strong interest in the hospice both from the academic and creative communities.

Research: St Francis has a strong track record with engaging in research and there is the potential for publications to emerge. This research could be expanded into a bid for funding, which could investigate the scalability and application of this research within other hospices that want to follow the process created with St Francis.

Although these goals aimed to set out how the hospice could use this research, they did not tackle what it meant to each party involved. At the base of it there was a disconnect in our own perceptions of research. Since the research was not aiming to work with large groups of patients or use established interviewing techniques, there were questions of validity raised, both towards the integrity of the research and towards the researcher's ability to develop an ethical practice that was not formally grounded in clinical practice. Validity can become a contestable term in practice research; Lather (1993) shows how validity has historically contributed to a particular mode of knowledge generation. Rather then dismissing validity entirely, she constructs her own notions of validity from a feminist perspective to introduce the term 'voluptuous validity'. This extension of the problem of validity to include a leaky, runaway, risky practice, constructed through self-reflexivity that brings with it a questioning of ethics and epistemology, seems a good fit for practice research that deals in public engagement. Grey (1996) also responds to the challenges of a developing culture of practice research by identifying examples of duality such as "subjectivity versus objectivity, internal versus external, doing versus thinking and writing, intuition versus logic" (p.7) that artistic methods were beginning to unify through postmodernism in the late 90s. However, although practice researchers have

developed a community that pushes at such dualities and forms of knowledge production, its wider acceptance is still being debated (Nelson, 2013).

The use of co-design also clashed with the principles of governance and ethics within the hospice. The article *Co-design and Implementation Research: Challenges and Solutions for Ethics Committees* (Goodyear-Smith et al, 2015) discusses some of the issues other researchers have faced when approaching clinical settings with a commitment to co-design. They describe the paradox in trying to use emergent co-design processes in "multi-stakeholder partnerships" which include "rigid pre-specification" that are at odds with the nature of the co-design process. They also indicate the time it takes to build trust, not via "one-off procedures that can be ticked off" but intricate negotiations that occur on and off site (Goodyear-Smith et al, 2015). Seamus McGuinness (2016) for example discusses his experience of co-creation in relation to the *Lived Lives* project. He charts a process where multiple applications needed to be made to the ethics committee (p.152) including a participant arguing personally for their right to be named, in order for the systems to shift. In this way the ethics committee came to acknowledge the integral role that these families were having in the process of constructing the artworks.

In my own experience, long gaps in communication and a strict procedural structure for recruitment created delays and tension in the relationship. During meetings with the hospice team, it became clear that the research was not fully understood, as collaborators struggled on each occasion to describe the research. A shared language was grappled with but formed on an uneven ground. From the hospices own institutional understanding to the clinical background of those within the team, it seemed as though the more we shared the more it highlighted our differences. These differences can also be connected or linked to different perceptions of design. Even the word design can have multiple layers of meaning within a hospice setting as described by Bate and Robert (2006). They consider the fundamental difference between the perception of design and the function of working with people in a co-design way. By charting the range of practices that have emerged from the various forms of design, they focus on the contrast between implementing a co-design or a re-design process. This rests upon the over use and blanketing of the term 'patient centred' which has become a phrase synonymous with development.

The paper questions how design is currently used to create a patient centred approach. They ask what it means to be patient centred: is it to enhance

performance through process design, to engineer new safeguards for patients, or to have a deep engagement with designing "human experience, as distinct from designing processes" (Bate and Robert, 2006). This is an important distinction to make, as human experience is less tangible and objective than the previous two goals of enhanced performance or safeguards. Even though my research was not involved in re-designing the hospice or working with large groups of patients, it is clear that the term design has come to mean many things within the health sector. Therefore the use of design research within these settings and the one I am working in, in particular, can make it confusing when considering what partners can expect when agreeing to take part. Hospices' expectations of design will correlate with their own understanding of how research functions within the hospice as a setting and the safeguards that they feel should be in place.

Time and Scale

The contrast in the partner's understanding of practice research and design research meant that time and scale were two of the parameters that shifted significantly across the process of collaboration. This was challenging, as time was both being stretched and planned for within the collaboration. For the hospice there was no urgency to complete the research as although advantages were articulated the goals were not tangible enough to need completion. Unlike elements of re-design that would have a direct impact on large communities within the hospice, the co-design process targeted a select few. There is no clear definition of how long it takes to build relationships, navigate ethical practice or recruit. However, as a PhD candidate time is one of the pressures that needs to be well planned for. So we entered into a balancing act that centred on persistence and timing. My need for research to progress more quickly created a tension between the research objectives and the hospice's need to provide a rigorous framework for engagement. The main challenges for timing were ethics and recruitment. In both cases the flexibility of the research created an environment of negotiation where each element needed to be discussed on its own terms, and the structured stages of research within the hospice rubbed up against the flexibility needed for engaging in co-design. On the other hand, this also created more space for reflection and allowed a strong ethical framework to emerge through the developing partnership. Time pressure created a need for the research to move forward and to tackle these questions head on. A timeline has been created to show the research progression and how co-design (which will be further discussed in Chapters 4 and 5) is embedded within this process.

co-designers

collaborators

participants
practitioners

2012

1st Meeting of
the **Hospice of
St Francis** team
at the Death and
Dying in a Digital
Age Conference

2013

1st Meeting at the
Hospice of St Francis
with the Hospice
Director, the Director
of Education and
Research, and
the Director of
Supportive Care

Design Department
Goldsmiths
Ethics Approval

Letter of acceptance
of the **Hospice of St Francis**
as a research site to
begin application for
Ethics Approval

2014

Research Ethics
Sub-Committee
Goldsmiths
Liability Approval

Clinical
Supervision
Begins

Disclosure and Barring
Service Certificate

Final Ethical Approval
Hospice of St Francis

Recruitment
Begins

**situated
design**

2015

1st session
Freda
with **Stacey**

Meeting at St Francis
Coffee Morning,
1st Participant:
Freda

Recruitment presentation at
the **Hospice of St Francis**

**co-design
process**

1st session
Sam with **Stacey**
Anne is introduced to **Elwin** an
Art Therapist and her creative
practitioner for this project

2016

Clinical
Supervision Ends

St Francis opens the project to
Support Care Staff & Volunteers,
3rd participant:
Sam

Email for meeting after
referral, 2nd participant:
Anne

**co-curation
in-situ**

Group meeting
at Stockwell
Street Gallery

Group
co-curation
meeting

Exhibition
opens

2017

Filmed
Interviews

Exhibition
take down

Designing Death
Panel Discussion

Figure 11: A timeline presenting how the PhD has developed through engagement with the Hospice of St Francis, Goldsmiths and with the individual participants: Freda, Anne and Sam. It also shows how the research has been framed through co-design, situated design and co-curation. The top arc (grey) displays how these design processes have shifted the relationship between participants and practitioners so that by the final exhibition they are all identified as collaborators. To fully understand this development readers should watch the four Practice Films at this stage to familiarise themselves with all the collaborators.

On-Site/ Off-Site Challenges

The site of the research in Berkhamsted was chosen due to the Hospice's desire to be part of this research, although alternatives, such as St Christopher's in London were discussed during the first meeting on the 20th December 2012. It was clear that there would be challenges in working with an institution that took over an hour to access, including a train and a taxi ride. There were also benefits to working with a site that was further away. This related to some of the ethical concerns around having a clear beginning and ending to the project. It created clear boundaries where practitioners were unlikely to become people's primary support when engaging with them on a long-term basis or undermining any help they were seeking from the hospice itself. The physical distance to the hospice also meant that they had a clearly defined place where practitioners had to travel to from London, thus sessions had to be planned well in advance with additional e-mail or mobile communication in between. It also provided a strong goal for participants who will have their work displayed in a gallery in London as opposed to in the hospice or locally in Berkhamsted. Having said this, it undeniably created issues, particularly around recruitment, in which the processes that were used to locate people often felt untransparent and it was difficult to casually visit the hospice to see someone or attend an event that was not related to recruitment, which would have helped with integrating further into the community. There is also the financial cost related to this travel, with a return train ticket from London Euston to Berkhamsted costing £32 and a taxi from the station to the hospice £18. This made it important to reflect on each journey and use the time there effectively.

Ethics and Integrity

By working with two institutions that engage with their ethical procedure in different ways, a hospice's research governance and a university's ethics committee, this section will critically reflect on the role of ethics and integrity within this research. Ethics as a practice of care and ethics as risk management relate to each other as: the design and implementation of principles of care as opposed to legally planning for who pays when things go wrong. Both of these kinds of ethics have played a role in the research. This section will attempt to understand the risks involved in such research, which relies on engaging with people categorised as vulnerable by both institutions. It will also comment on the fact that the institution's approach to risk management involves pre-thinking and

planning for the worst possible scenario, which mostly does not reflect the reality of working with people and can predefine the nature of such research if the researcher is unable to navigate these conditions while keeping an open mind and getting their research signed off by an ethics committee.

Firstly I would like to address some of the preconceptions about bereavement being institutionally seen as a vulnerable condition and how this affects people's agency within the bereavement process (Vines, et al, 2014). While some researchers have used their experiences of designing with vulnerable people to consider how they form different kinds of users (Massimi, 2014), other researchers have looked more deeply into the meaning and value of vulnerability in relation to the human condition (Lagerkvist, 2016). The risk management approach to ethical practice views bereavement as the kind of vulnerability that is explicitly negative or diminishing, therefore difficult to engage with. Vulnerability is a term that is often used to define the bereaved as a group of people that need protection and should be approached with caution, preferably by those professionally trained to deal with them.

In practice, as Walter (1996; Ch.1, p.27), Barthes (1981; Ch.2, p.64) and De Wall (2011; Ch.2, p.65) show in their integration of personal experience with research, we do all have to engage with bereavement in our day-to-day lives. The clinical view of bereavement creates an imbalance of power where the person you are protecting will always be lower than you. It ignores that vulnerability, as a characteristic, can also create an opening that allows things that were fixed in place to be rethought. Emotional pain may be part of a process of change or deeper understanding, as Turkle experienced with the loss of her memory closet (2011; Ch.2, p.62). If vulnerability is seen as a kind of exposure or rawness (in material terms that could be seen as a rubbing or peeling back of layers) might this exposure not also reveal something? The use of the design lenses (Ch.2, p.69) coupled with a commitment to co-design attempts to push against an institutional approach dealing with bereavement and bereavement therapy. Instead it sites a shift towards a more equal collaboration. It can be seen as an alternative practice that allows for a different mode of exploring and thinking about loss.

Co-design fits well to these goals as it oscillates from the "protection of individual participants to the development of a relationship between researchers and community partners" (Goodyear-Smith et al, 2015). It is this commitment to active engagement that uses the background and training of researchers to care

for people within the research project without limiting their own agency or affect when research is positioned as collaboration. When considering the integrity of the research, it is therefore important to consider the vulnerability of the researchers, particularly when they do not come from a clinical background (Galvin, 2013; Moncur, 2013). This reveals questions about the nature of risk within this kind of research, including who holds the risk and how the risk impacts the way we bring ideas from theory to practice. It can be used to consider more widely how the evolution of ethics within research alters the nature of the research being undertaken, allowing the researcher not only to reflect on the ethical conditions of their own research but on ethics as a distinct thread in one's own research. The following sections will develop critical approaches to some of the terminology and bureaucratic systems used for defining ethical practice within the academic fields of art and design, particularly when researching sensitive topics through practice.

Ethics and Data in a Digital Age

In the digital age we are awash with data (Ch.2, p.34) we distribute much information about ourselves online but do not always understand the impact of this sharing (Mayer-Schönberger, 2011). This is significant: as we develop our digital identities we are becoming more used to differentiating what we would like to share and what we would like to keep private. Transparency is a growing principle in the area of data ethics (Turilli and Floridi, 2009). It states that we should know and be able to choose how much data is being kept, how and with whom it is being shared, and what happens to it after we die. These shifts are relevant to our contemporary understanding of ethical approval within universities. Transparency could be used as a set of principles, rather than a tick box to guide any practice research that aims to become public. In general, it seeks to question whether the use of forms in applications for ethical approval are too standardised for practice research that, once public, will undoubtedly end up online. To do this I will draw attention to the language used within ethics applications and reflect on which questions need clarification and how this constructs a particular mode of research, particularly in relation to the participants' personal data section.

Within the ethical approval forms (App.2, p.172) you can see that, depending on whether you answer yes or no to specific questions, you will need to provide clarification to ensure that the research is ethical. For example, if your research includes data, the questions asked are: "Will the data be anonymous?" and "How

long will the data be stored and how will it be eventually destroyed?" Both questions imply a certain ethical stance: data should be anonymous and destroyed after a particular amount of time. Although these may seem to be fairly standard questions within an ethics form, they are loaded questions for this research due to its commitment to co-design. From the co-design perspective exhibiting together means sharing the responsibility and transparency of the research process with my participants. It would therefore be ethically wrong, in terms of my duty of care as a co-designer and as the principal researcher for the data, if people's names and their involvement in the project would be kept anonymous even though they desire the opposite. When working with people, as participants with an active choice in the process, it is important for them to have the option of claiming their thoughts, processes and actions within the research. By placing participants on the same level, this is part of the process of the researcher protecting those that they are researching and the power dynamics that are implied through the exhibition of this research.

The ethical approval forms also read clinically, as they were constructed for research that works with people through scientific rather then design methods. It is critical to mention that if you are going to keep data confidential, anonymous and destroy it, you do not need to clarify how your research will deal with this data in an ethical way. This implies that the data holds no meaning to the people who have given it to you. Gunaratnam (2009) describes the responsibility of the researcher towards the stories of interviewees and the fact that this telling of their lives may be of no small consequence to them. Within this institutionalisation of ethics, people's lives and stories are limited to data. It implies a judgement on the kinds of research being promoted as ethically safe. Ingold (p.4-5) also weighs in by considering his relationship to fieldwork. He describes participant observation as the speculative ambition of anthropology. This is collapsed into ethnography (through documentation) only when it is forced to succumb to an academic model of knowledge production where people become empirical material to be interpreted. He states that "participant observation is absolutely not a technique of data collection. Quite to the contrary, it is enshrined in an ontological commitment that renders the very idea of data collection unthinkable… in a way participant observation is knowing from the inside" (Ingold, 2013: 5). Gunaratnam and Ingold share a commitment to people as opposed to data and reflect on new ways that ethical principles may extend beyond ethical consent and usage.

81

Exhibiting Practice Ethically

Despite the ethos of individual researchers, institutionally these processes are becoming more rigid and structured; as Back (2013) claims in "an increasingly regulated university context the preoccupation with 'ethical approval' and 'risk assessments' … [produces] something close to a kind of 'ethical hypochondria'" (p.15). This instrumentation means that research is being judged through the institution's liability as opposed to the ethics of care. Researchers need to think carefully about the time and commitment required for doing ethics in order to effectively negotiate and argue their case. The fact that the forms imply that there is something inherently more worrying about research which is transparent and in which participants want to be named says much about the systems of ethical approval and the need to develop more diverse approaches to the evaluation of practice research (Goodyear-Smith et al, 2015). When exhibiting collaborative practice, to enforce anonymity would at best undo the principles of collaboration and at worst claim the voice and creative output of the participant under the name of the researcher or artist (Mahony, 2001). It could also be seen as disenfranchisement of the dead by not allowing them to be named. The openness of the research, both to the participants and to the public, also undoes to some extent the nature of anonymity. Having an exhibition shows that there is a desire to share the experiences of research that are embodied in the practice (Jungnickel, 2010).

Therefore the goals of ethics within this research are reframed through practice. As participants grow confident in their development and become collaborators in the research, they desire to be named and given status within the exhibition, even if this simultaneously makes them anxious at the prospect of revealing themselves (Ch.5, p.128). It is not possible to pull apart the data from people and their practices. The public nature of the exhibition means that this will be shared and documented. The documentation will be both formal and informal. Making the exhibition public and working to this goal with participants leads to the situation that the destruction of data used within this exhibition will not only be impractical, it will be impossible. As with any private view, people will enter the space. They will take photos, write tweets and blog entries that will remain online, and – although this is not the 'raw' footage from interviews but explicitly information that we want to present – it does present a challenge for what is ethical in this circumstance. Perhaps there is a distinction to be made within the co-curation process in relation to the choice participants place in what is on

display and making sure there is a shared understanding of what display means within this context.

In line with developing a shared understanding of what exhibiting means for this process, prior to participation it was important that participants had a deep discussion about how they were going to be involved in the research. This included what would be required from them and what they would get out of participating. They were also given the control to pull out of the research at any stage if they were no longer able to continue. This was set up as a longer conversation, which went into detail about the research through the consent forms and information sheet (App.2, p.188) at the recruitment stage. I timetabled at least an hour in cases where people expressed a strong interest in participating. This introduction session also aimed at explaining, in some depth, the role of the exhibition in the research, rather than leaving it as something that evolves out of the sessions. It was important that exhibiting was not positioned as an afterthought and that the participants were thinking about this experience as both personal and public simultaneously from the first session.

This is quite a diversion from the conventional art therapy approach to confidentiality. I discuss this in the next section as one of my research contributions, including how it might impact on art therapy (Ch.4, p.101). There is a spattering of literature associated with exhibiting art therapy, as it is traditionally treated as part of the clinical notes. Notable exceptions are some of the case studies within *Materials and Media in Art Therapy* (Moon, 2010), which presents a different approach to traditional art therapy, and Westwood's mapping of different pedagogical approaches to art therapy in Australia such as 'surviving through art', 'arts-based inquiry' or 'arts as therapy' where members of staff will regularly exhibit together to inform their teaching methods (Westwood, 2013). The *ATOL: Art Therapy OnLine* exhibition catalogue (2014) also shows a diversity in practices both from art therapists and occasionally their clients e.g. the *Corinne Burton Memorial Trust*, which features two clients who are named as producing some of the collection of artworks shown. Outsider Art[60] is another traditional form of exhibiting associated with art made in a medical setting; historically psychiatric patients produced this. One of the deeper considerations within my research is how to curate an exhibition that fulfils both the research and the participants' goals without unbalancing the power dynamics that are always implicit within research. It is also important for consistency to make sure all

---

[60] There is friction in the two communities of art therapy and outsider art whereby both communities were founded on the relationship between art production and patents but have core differences in their ideologies and focus (Poling, 2015). These differences may intensify the underlying discursive issues when discussing exhibiting within the art therapy community.

practitioners take a similar approach to the consent forms, as a way of transparently talking to people about what this project entails and what their role is in it.

These ethical principles of transparency and flattening hierarchies are not linked to liability but to practices of care that are negotiated in open and intuitive discussions with participants in their homes. The research I have undertaken is not risk free but does aim to explain in clear and simple terms what will be done with the participants' work and why exhibiting is important to this process. This includes what I am going to keep and what they will, what I will do with the research, how the exhibition will be curated and more. There is a commitment to being as transparent as possible throughout the process and acknowledging people's fears and vulnerabilities. In addition to this – by not doing therapy and spacing out the sessions; by conducting the research as an extended collaboration over two years; and by making the works specifically to be exhibited – I am addressing some of the ethical principles underlined by Mahony (2010) in her PhD *reunion of broken parts' A therapist's personal art practice and its relationship to an NHS outpatient art psychotherapy group: an exploration through visual arts and crafts practice*. As an art therapist she provides an extensive discussion of consent and the power relations that are at play in art therapy when a client is asked to participate in exhibiting.

Despite the fact that I am working outside the therapist/client model there will still be power relations to consider. After visiting a range of exhibitions, Mahony describes the impact this has on her practice including "the ethical issues of working with people in vulnerable states and unequal relationships … [the] resonances of material practices and sustained attention to detail …[and] the importance of social comment and curatorship." (Mahony, 2010: 193-194). When working with the bereaved on any form of artistic collaboration it will bring up painful encounters, and it is important to ethically mediate the work so it does not become too raw. The process of ethics must be continuously negotiated on site and at every stage of the process from first meeting to exhibiting. When collaboration is not approached ethically throughout the process, it can be confronting and exposing. Participants can feel used. Mahony (2001) describes the experience of seeing an exhibition where artists aimed to collaborate with patients but did not understand or empathise with the process of therapy. The work showed "the rawness and pain of … undigested … 'therapy'… unworked through, unresolved and unintegrated" (Mahony, 2001: 59) and this left participants feeling like they had been "used as sort of tubes of paint for these

artists" (Mahony, 2001: 60). As practice research develops and extends its role towards public engagement in sensitive contexts, it is important that ethical principles evolve to meet the needs of these emergent forms of research that need ethical scaffolding.

Ethics in Transition

Beyond the critique of ethical procedure in the previous section, ethics remain key to the process and practice of this research. On occasion through filling out forms, but also as a genuine imparting of knowledge and wisdom from collaborators, colleagues and partners at The Hospice of St Francis. This advice-based ethics has really helped to develop the research goals and change the fundamental nature of the research undertaken. It allowed the experience of other researchers and practitioners to be imparted and matured within the research practice.

There were three main changes that were implemented for ethical and practical reasons. These changes shifted the nature of the research in interesting ways. They included the research moving from working with artists or designers to art therapists. This change was suggested as a way of using the knowledge and safeguards of art therapists to create a stronger team that would be able to care for and support each other. The change of setting from hospice-based to home-based research: This move was more to do with timetabling the use of the hospice for sessions but had a strong impact on the implementation and the participant's relationship to the sessions. By conducting them in the home it created a situated home-studio environment (Ch.4, p.114). This shift meant that the liability of the research moved from the hospice to the practitioners and therefore liability insurance was needed. Employing a clinical supervisor was suggested by the hospice to make sure that the research is implemented in an ethical way and that I have someone with a clinical background to refer to.

In different ways these three changes framed and constructed the focus of this thesis. Working with art therapists meant that I have the opportunity to reflect on how this discipline uses arts practice in relation to my own understanding of practice. Working in the home shifted the focus from the hospice towards how things and environments are integrated into the design process. Clinical supervision enabled deep critical reflection on the hospice and my own research when situated in this environment.

Clinical Supervision and Self-Care

Although clinical supervision was originally one of the ethical stipulations in the hospice's research governance framework, it became a fundamental part of the research practice. It engaged with reframing the issues around recruitment and facilitating a series of reflective conversations (Schön, 1982). It also stimulated a practice of self-reflexive writing, which extended into the home sessions with participants. The notes from these sessions have been explored and expanded on within this section. As a general overview, the clinical supervision aided in developing the research within my chosen site and gave me a deeper insight into the nature of hospices in relation to key issues such as timing and recruitment. It also provided the necessary emotional support that is needed when dealing with risk in research. By referring to risk here I do not mean the risk for the participants, and the ethics associated with this, but risk for the researcher in actually being able to conduct the relevant research and in being flexible enough to let the research change as the situation evolves and as participants join the project. There were three main ways that this impact was felt within the research: (1) clinical supervision provided real understanding and input into the hospice environment from an outsider of the research (2) emotional support and strategic advice, it is important to think about the research in both ways, and (3) a sounding board, someone who is there for you to provide critical conversation.

Self-care was a topic that had been previously discussed with both my PhD supervisor and the team at St Francis, but it was predominantly focused on the emotional support that may be needed when working with people going through bereavement, as someone who had little experience and no formal training in this area. As it turned out, the most emotionally turbulent time was not working with my participants, who have been an insightful and pleasurable phase of the research, but actually the stress and anxiety related to working through the recruitment processes with the hospice. My clinical supervisor, as an art therapist with a strong understanding of arts research in hospice contexts, was able to advise both on the creative and practical aspects of developing the research and to give feedback on the wider place of this research within the field of art therapy and development of creative research within hospices. This included helping me to conceptually place this research in the art therapy community and understand

its impact. There were five sessions in total occurring over a period of nine months[61].

Ethics and Clinical Supervision

From the first introductory session it was clear that the clinical supervisor understood and approved of the ethical preparations that had been made for this research. What was discussed in more depth was the relevance of flexibility within the co-design approach. We considered the role the complexity plays within the research, including how it uses the flexibility of the methodology to avoid a one size fits all model while still creating research that does not need me as a creative practitioner in order to exist. This is due to the way that an individual approach is solicited, within a flexible framework. Each collaboration must develop its own approaches to the collection, based on a unique set of factors e.g. a person's life, range of things within the archive, creative ability or material affiliation of the participant. This range of factors develops a scalable methodology, that despite its complexity, can be replicated as long as the participants and practitioners[62] are able to collaborate and understand the overarching themes that frame the process.

Another piece of advice that was taken on board was the frequency of sessions. Although the schedule for physical visits evolved based on people's own commitments and lifestyles, it was important to consider that the closer together these sessions were planned the deeper the emotional enquiry would go. In contrast, the further apart they were the more the sessions would become reflective, acting as a gathering point for thoughts and feelings from the surface of the mind. In practice this reflected the nature of the bereavement, as one of the participants, who had a more challenging bereavement, began by seeing their creative practitioner on a weekly basis and, as the research progressed, then switched to bi-weekly or monthly sessions. This participant was still processing the loss had a much more visceral, iterative, material investigation (App.4), whereas the other participants who had already done much of the initial meaning making were able to begin with monthly sessions that were supplemented by e-

---

[61] Each session lasted one and a half hours; timing was clearly discussed and managed. The sessions took place on the: 2nd October 2014, 5th November 2014, 3rd December 2014, 5th March 2015 and 2nd July 2015. Most sessions were conducted in Goldsmiths, Laurie Grove room 13.1 when available.

[62] Originally I had recruited a team of five art therapists to participate as creative practitioners. Following the 9 month recruitment cycle, people's time commitments had changed and only two of the original five were able to participate. One took on the role of a creative practitioner and the other became a participant in the research. It may also be considered that, through training and perhaps working with the team of art therapists that were unable to participate in this project this could develop into a wider research project or professional practice.

mail, Skype or phone conversations to support this development and took a more conceptual approach to the making.

Insight into Hospice Environments

"Following on from last month's session on ways of pushing forward recruitment and being bolder in my use of timelines and goals. In this month's session we started by analysing, in some depth, the responses I have been receiving from the hospice...This led to a discussion around the make-up of the hospice itself and concerns around internal politics and the need to be seen to be 'making an effort' interfering with the project itself."

(An extract from my clinical supervision notes on the 3rd December 2014, App.2, p.192)

The hospice is a busy environment with many very immediate demands on people's time. As we analysed my e-mails, which had aimed to be empathic, we considered whether the tone was helping to put these emails at bottom of people's priority list. The advice was to be bolder when contacting the hospice. This was challenging at first but was core to the progression of the research. It aimed to couple this tone with a sense of what particular members of the team will benefit from when participating, including a conceptual shift in seeing the research as an opportunity that could offer the hospice additional support to their clients and publicity through the exhibition, rather than a demand or a burden on people's time. It was also important to strategically consider who I was speaking to and try to address the things that would appeal to them in order to get the research moving. This also included asking direct questions about how my material is being distributed, who is responsible for it and giving clear deadlines. The issue that was addressed here was my own empathy for people's workloads. Therefore one of the main strategies put into place, through the clinical supervision, was to create a deadline with the hospice after which – if the recruitment numbers are not fulfilled – I needed to be more actively available on-site to talk and answer people's questions about the research.

Another strategic part of the research that was addressed during supervision sessions was the lack of response to e-mails and the fact that, perhaps instead of saying no or I'm too busy, it was easier for members of the hospice to just not reply. It was suggested that this is perhaps due to the demanding environment of the hospice, in which people are always asking a lot of you; and as they are very

ill or dying it is very difficult to say no, so saying nothing somehow becomes part of these environments. It has been quite enlightening to see how the hospice works as a very different institution to the university. It has its own protocols, anxieties and red tape. This included the way they felt the need to move systematically through the various stages of recruitment that makes sense to them but to an outsider seems laborious and inefficient compared to direct recruitment. This was exemplified when entering the hospice, where during casual conversations support staff would mention people they know that have a strong connection to technology and which would obviously be strong candidates for recruitment, but could not contact them due to the protocol.

One of the reasons for this is their understanding of hospice-based research, which has a consciousness of 'human subjects' in line with the history of biomedical research and has experienced an increasing regulation in the past five decades (Goodyear-Smith et al, 2015). This anxiety and formalisation has led to the belief that potential participants must approach the research themselves as the hospice cannot be seen to be putting pressure on people to participate. This includes any forms of targeted or direct recruitment e.g. sending a flyer via e-mail to specific people that have a creative or technical inclination. This is also supported by the hospice's assertion that participants will be more committed if they approach the research than if they are offered it. Clinical supervision was able to keep my spirits up during this time by helping me keep in mind that these struggles are an integral part of the process and that they are helping me to understand more fully the hospice environment.

Emotional Support

"There has been very little movement on recruitment. I have reached the point where I need to have a deadline for this process and begin to consider alternative ways of writing up my thesis and the experiences I have had with the Hospice over the past four years."

(An extract from my clinical supervision notes on the 5th March 2015, App.2, p.192)

This conclusion is fundamental when trying something new and taking risks within your research, particularly in terms of relying on an institutional partner for recruitment. The lack of control in these situations was addressed as an important aspect of self-care within the research. These sessions also involved coming to terms with the fact that, if I was unable to recruit, I may not have

been able conduct the research I had originally wanted. That I would have to write-up what had actually been produced through the research to date. This involved setting a deadline which would be the final cut off point. Although it was painful to think about writing up without having achieved the recruitment goals it did help to break the rigidity of the research and open it to being situated in practice. It also provided reflection on the richness of the narratives heard from so many different perspectives, which gave the topic breadth and an ability to add to current research in a practical and future-facing way – as something that can be discussed in an open way throughout my research and practice.

One of the practical ways that the clinical supervisor was able to help with this was simply to empathise with the frustration and to encourage me to continue pushing for more face time at the hospice in which to present my research. The deadline for progression without the hospice was set to just after the 10th March 2015 in which I presented my work to a mixed group of bereavement councillors and volunteers at St Francis. The aim of this presentation was to close the recruitment cycle. By presenting my research in a compelling way that was very geared towards personal engagement and storytelling, i.e. my gran's thimble collection (Ch.2, p.45), it showed the accessibility of the research and gained support from the bereavement team at St Francis. In addition it aimed to exclude academic wording such as 'PhD' to allow the collaboration to come into full focus. This public presentation was also used to acknowledge the fears that potential participants may have that had been documented for me by the hospice. Some of the fears documented included: the bereaved worrying about whether they were creative enough to participate in the practice; the bereaved worrying about what they might find if they began to look into the digital archive, particularly people's Google search history and thinking that they would need to become a kind of detective to take part in the research; the bereaved worrying about the digital medium itself and considering if they have enough digital content to explore within their collection. These fears were addressed indirectly within the recruitment presentation, which aimed to widen the scope for recruitment and emphasise the flexibility of the research (presentation, App.2, p.199). We can see in Chapter 5 (p.128) that although Anne does want to participate, she shares many of the fears identified here. However, through her collaboration with art therapist Elwin, she is able to grow her confidence, overcoming these barriers and viewing her participation as a distinct form of personal growth.

Direct vs Non-Direct Recruitment

Recruitment was a sticky issue throughout the development of the research; it proved a challenge both for myself and for the team at St Francis, causing undue friction in our partnership. This was linked to the issue of direct vs non-direct recruitment due to the complexity of the research, in the sense that there was no clear outcome (i.e. a memory scrapbook or even a digital locket) that could be shown to people in advance. Neither was there an established process like art therapy that people could easily identify with and pass on to others. Other researchers have identified similar issues with recruitment when working with design and bereavement in a bespoke way, recruiting their participant through personal contacts (Moncur et al, 2015). It was clear that there would need to be a more nuanced form of recruitment in order to help people understand the potential benefits of taking part. It was key to define these benefits in more detail in order to understand why people would want to participate.

For the practitioners it was positioned as a way of reflecting on their own practice and being free to try new things. The co-design process was situated as a way to help the creative practitioners who are art therapists to reflect on their own practice. Rubin (2016) supports this connection between collaboration and art therapy in the introduction to her edited collection *Approaches to Art Therapy: Theory and Technique*. She refers to Shirley Ridley's systemic approach to art therapy, which includes an element of co-constructing the process with the client and becoming a collaborator in the process of therapeutic conversation, including the relinquishing of power and addressing of these embedded dynamics (Rubin, 2016: 5). This process allowed the art therapists to shed the frame of therapy by questioning 'normal' art therapy practices and engaging in a design approach to working with people, outside the client model. It also allowed them to consider the scope of exhibiting as part of this creative collaboration.

For the participants the research offered a way to isolate the space and time to deeply consider those they have lost and to create artistic interpretations of the things that have been left behind. This aimed to help them reflect on their lives, translating their presence into artefacts to be exhibited. Although not all participants will have the same experience of the research and they will explore different relationships, making and exhibiting can be seen as a way of re-framing that relationship and reflecting not only on the dead but their own personal development throughout the project (information sheet and project descriptions, App.2, p.188).

As part of the research governance people could not be targeted directly, as reflected on during the clinical supervision (Ch.3, p.88). It became clear throughout the process, that as the research was focused on the bereaved rather then those dying, many of the young people who had experienced bereavement do not keep close ties with the hospice and do not attend as many of the public event as those of retirement age. For a research project whose main focus was on exploring the digital data left behind after death, there was a need to reframe it. This took over nine months – from receiving approval of the Disclosure and Barring Service in August 2014, which allowed me to begin recruitment, to recruiting my final participant Anne in early May 2015. This involved testing strategies and a critical reflection on what the core of the research was. The research questions were developed as participants were recruited. Below are some of the strategies that were employed and a description of the results of their usage both from my perspective and with some reflection on e-mails from the hospice.

Flyering: It is hard to tell how each of the three iterations of flyers faired as it was unclear exactly how the flyers were distributed or to whom, whether they were announced or simply hung up. The flyers were re-designed three times in consultation with the team at St Francis in order to achieve the right tone and visual imagery (see below). However, after a month it was clear that this method of recruitment had produced no results. The hospice stated at a later stage in the process (via an e-mail on the 24th November 2014) that the material was taken to two Bereavement Groups and that time was taken to speak to each visitor from the group individually, encouraging them to think about participating in the project. They stated that this had been challenging for a number of reasons: one of the reoccurring themes was peoples' struggle to understand the complexities of the project and peoples' concerns that they would not fit the required criteria. During the recruitment process, as suggested by my clinical supervisor, I set my own deadlines, which allowed me to rethink strategies when each of these stages was passed.

Figure 12: Final designed version of recruitment flyer incorporating feedback from the team at the Hospice of St Francis.

Access to events and public presentations: As it became apparent that more detail was needed to help people, including the hospice team, to develop a clearer understanding of the research, I believed that it would be best to target events at the hospice for recruitment. The first event I targeted (based on feedback from my art therapist consultation team) was the hospice's series of remembrance events. I believed the people attending these would be in a more reflective frame of mind and thus more open to considering the benefits of this research. I also thought that my presence would help people to understand the nature of the research and how they could benefit from taking part. I was then informed that the remembrance events and memorial evenings were not a viable space for recruitment, as they are very client/carer led and more focused. It was suggested to me instead that I attend one of the coffee mornings they hold at the end of each month, as they are open to the public. Upon arriving for the coffee morning however it became clear that it was generally attended by older people who have lost a partner and thus do not typically have a large archive of digital data to explore.

The hospice team stated that they invited me to come and experience the challenges they had been facing in recruitment. Attending the coffee morning (31st October 2014, 10.30 - 12:00), where a number of bereaved people were present, gave me the opportunity to speak to people and experience first-hand the sensitiveness and challenges of such conversations, which take time and skill to manage. It became clear that some of the complexities surrounding finding suitable participants were related to the fact that my research aimed to explore the digital component in depth and that there was to be an exhibition of what was produced. It seemed clear that one of these criteria would need to develop with

the project and thus the digital component gradually become less important. The focus on having a mixed archive of digital and physical things gave the research more flexibility, as I explored when discussing De Waal's netsuke and the materiality of things in Chapter 2 (p.65). This also enabled the visualisation of research through the collaboration itself in two different but complementary ways, and gained more relevance to building the participant's sense of belonging. This was not only a turning point within recruitment but also within the research itself as it led to a much wider conception of materiality. As part of this loosening of criteria, it was at the St Francis coffee morning that I first met Freda.

Social media: This was an attempt to widen the scope of mouth-to-mouth recruitment and to see if I could use the large following of St Francis' Twitter and Facebook pages[63] to aid with recruitment. Having designed a more user-friendly introduction sheet (App.2, p.187), the team used Twitter and Facebook to further promote the research. However, although St Francis did add a couple of posts relating to my research on these social media platforms, their profiles mostly focus on the charity side of the hospice. These act more as a public face for raising money and can be quite separate from the care side. It was difficult for the research message to attract attention and it was slightly lost within this pace and type of content.

Volunteer network: In addition to the social media distribution, I also asked for my information sheet to be sent to the volunteers' network, who are predominately made up of people who have had a close family member or partner die in St Francis and wish to give something back. This approach was unsuccessful in spreading the word though, due to the fact that those managing the network were using it to promote a wide range of activities related to the hospice. I saw that when the e-mail was sent out, just after Christmas (on the 12th January 2015), my recruitment information was sent with a mix of content ranging from recruiting new doctors to choir activities in a single newsletter, which made it quite easy to miss, and it limited the detail that could be given. Following this I moved on to other strategies.

Letter to the bereavement team: In order to develop a more direct recruitment method based on the lack of events to attend and a shifting timeline I asked for a consultation with the St Francis team. Following on from this consultation with the Clinical Bereavement Lead, it was suggested that I draft up

---

[63] The Hospice of St Francis's Social Media: Facebook: https://www.facebook.com/thehospiceofstfrancis/?fref=ts /Twitter (@Hospicstfrancis): https://twitter.com/Hospicstfrancis [Accessed: 5th October 2016].

a very personable letter addressed to St Francis' bereavement councillors asking whether they could discuss the research briefly with clients who they think may have an interest in being involved, and ask if they would be happy to be contacted with some more information (App.2, p.187). When this did not produce results it was suggested that I present at the **Bereavement volunteers training evening**, on the 25th March 2015[64]. This would be attended by a mix of the St Francis bereavement therapists and the volunteers. This presentation needed to hit the right note; there was a deep consideration of what the right content and language would be in order to tell a story that would help people to both understand and see themselves participating in the research (App.2, p.199). The presentation was successful in the sense that it clearly sparked interest, particularly among the bereavement team, many of which came to talk to me further following on from the talk and some even expressed an interest in becoming participants themselves. However, it was not until a few weeks later that I had a second breakthrough. One of the bereavement therapists had been able to successfully discuss the project with one of her clients and I found Anne who was interested in participating in the project.

Inclusion of members of Support Care volunteers/ staff: The third breakthrough in recruitment came through a suggestion from the St Francis team to open up recruitment to the Support Care volunteers and staff, as some of them were interested in the research. This led to Sam, who previously had been recruited as one of the practitioners, moving across to being a participant.

It is clear from the above that recruitment was one of the biggest challenges within this research. However, the subsequent recruitment of the three participants Freda, Anne and Sam has also been one of the successes of this practice research as it was able to maintain both its flexibility and its commitment to exhibiting practice[65]. It also evolved the research as it opened a new approach to materiality, which considered the digital as a unique but not isolated component of the making process.

---

[64] This event was due to take place on the 3rd February 2015 but was cancelled on the same day as the car park was iced over and it was deemed unsafe to park vehicles. Due to the hospice's busy schedule the next available date to present was the 25th March 2015.

[65] By choosing to work in a small English town on the edge of Hertfordshire, the people using the hospice, as well as the staff were fairly homogeneous. My participants are reflective of this. As this research aims to understand the relationship between materials and loss in an individualised way, which means that cultural and socio-economic differences were minimal and this will have played a role in the way the research was perceived and participated in.

Multiple and Shifting Roles

This research is formed through building relationships between people, and the relationships that are being constructed with the artefacts they are producing. Therefore the way I engage in this process, as a researcher, is integral to the way it develops and how much agency people have within the process. My role as a researcher could be considered as the frame that contains all the other roles. This maybe accurate in some ways as the project was initiated as research, but as the research has progressed, the multiple roles have folded into each other and become enmeshed.

I find myself increasingly being both a researcher and a practitioner simultaneously, or having to stop my research self from guiding the curation process too heavily towards my own research goals, but still finding a way to keep these present. Personal negotiations have been important to my own understanding of what it means to be a researcher, practitioner, designer and in this research specifically a co-designer, including the knotty questions of where my commitment to being a researcher is challenged by my own desire to open up my research in an inclusive way. This commitment to co-design meant that it was essential for me to be one of the practitioners working within my research, as it is this experience that gives me a rich vocabulary to describe the practice and to critically reflect back on how the various stages of the process have evolved my research questions and constructed the nature of this research, shifting the centre of enquiry.

One example of this kind of internal conflict between the researcher and the practitioner is the desire to record everything. As a practitioner I am aware of the fact that being recorded changes my relationship, both to the participants but also to the making process. It removes the ability to just try things and play with ideas, crucially to be able to fail and renegotiate a more fertile route, which is critical to design practice. This lived experience generates meaning that is emergent, it "is generated by 'feelingly' thinking about the interconnections between past and present events" (Telier, 2011: 109). It would feel different if the sessions became a formalised part of the research, shifting the focus and changing what is produced. By limiting myself to taking notes (when needed) I am free to put the researcher slightly to the side while being a practitioner and to focus on being in the collaboration and part of the making process. By attempting to seep into the process and let it flow (Gunaratnam, 2009), I am able to loosen the ownership and trust in the participants to help guide me to make discoveries

about my own preconceptions of the research[66]. The exhibition is a key focal point for this, as the interviews are not the end result of the research but instead a reflection point for the forthcoming co-curation and finalisation of artefacts in February 2017.

Exhibiting is crucial to the validity of the practice as it allows the written research to be interwoven in the process without dominating it. The recorded interview essentially enters at a particular stage of the research (6 months before exhibition, August 2016) to redirect the focus of participants towards the goal of making a presentation. This includes what experience they want friends and family to have when they attend the exhibition. It also allows the art therapist who is working as a creative practitioner within this research, Elwin, the freedom to not be confined to the research goals but to explore his own process through new techniques and co-design methods. By promoting active rather then passive engagement with questions of display, this collaboration promotes the participants and practitioners to see and reflect on the artefacts in different parts of the research e.g. with their practitioner in sessions, in the interview portion of the research and following this within the wider debate of the exhibition.

The final interviews with each of my three participants in addition to myself and Elwin, consisted of three questions that asked the interviewee to describe the process of collaboration, the artefacts being produced and the final exhibition. Prompts were used to guide the conversation and focus in on particular areas of interest e.g. labelling. By keeping the interview short, aiming to be ten to fifteen minutes long, it does not provide a deep reflection or enquire into a specific range of questions but rather seeks to gather the stories that have been building at the surface of people's consciousness, in response to the project. This narrative approach to the interviews (Gunaratnam and Oliviere, 2009) trusts the knowledge of participants as collaborators by allowing them to tell their story and frame their own approach to what is produced through this research. This is developed over the course of the collaboration as people begin to ask what the participants are doing e.g. friends, family, colleagues. They are beginning to find the words that feel right to describe it, testing them by saying them and letting them settle. So rather then the final reflection being a chance for me to delve deeply into what people subconsciously felt about taking part or how they have emotionally evolved in terms of their loss, this remains an enquiry into making

---

[66] This was also aided through the clinical supervision where I acknowledged the fact that I could not tightly control the process of recruitment, which helped to loosen the bonds towards specific outcomes of the research.

with things as practice research with the final interviews focusing on the reflected meaning of the process and artefacts produced.

IV.
CO-DESIGNING AND MAKING WITH THE BEREAVED

Co-design and Public Engagement

Design is opening up. As mentioned in Chapter 1 (p.36) by engaging in systems, services and design thinking both meaning and understanding of the design process have expanded. Over the past 40 years it has moved to further integrate users into the design process through user-centred design and participatory design, followed by co-design and co-creation (Sanders and Stappers, 2008). These shifts in design thinking to become more collaborative have in turn broken down the role of the design expert within these relations. With it come questions of what role designers have in these systems and how design processes can be seen as the product of a design investigation. By engaging these systems in an open and flexible way, designers are grappling for both problems and solutions simultaneously (Steen, 2013). This process can allow for users or participants to become collaborators, and deeper questions need to be asked and tackled: how do these collaborations actually work, and where is the collaboration is situated? Furthermore, how do you bring people with different skill levels into the process of making towards an exhibition?

Although co-design is being used to a greater degree within the business, health and social sectors (Bradwell and Marr, 2006), increased usage of the term needs to be combined with an emphasis on how the actual design processes function to avoid tokenism (Lee, 2008: 31). The introduction of living labs as situated environments is one way of addressing this issue (Tellier, 2011: 179). These labs aim for co-creation with real users on a long-term basis and show how design is grappling with questions of ethics and pragmatism. They try to understand the parameters for setting up deeper design and conceptual processes without losing inclusivity. The establishment of design participation has also led to the creation of a range of design tools, method kits and design probes that aim to help people engage with the design process. However, as these tools become standardised they run the risk of fixing a specific mode of design collaboration, which needs to be questioned further[67]. The toolkit approach may also solidify certain power structures and re-assert the role of the designer within these relations, or

---

[67] Within this blogpost *Mapping Social Design Practice: Beyond the Toolkit* Lucy Kimbell questions the way that toolkits have begun to materialise and produce artefacts for supporting design process. She questions how these kits address concepts of legitimacy, power relations, foster wider conversations, cross boundaries of practice and create specific modes of working (https://mappingsocialdesign.org/2013/11/19/mapping-social-design-practice-beyond-the-toolkit/). [Accessed: 8th September 2016]

alternatively allow non-designers to apply it as a one size fits all method. Having said this, the movement of design towards inclusivity makes it a good fit for use within innovation, reform and social activism in a wide range of sectors, which in turn strengthens the position of design within society. This is often termed redesign, social design or design for social change. Additionally, the use of design is not only being instigated by designers but by the DIY and maker communities, extending design beyond the realms of professional study (Lee, 2008: 34) and intervening in design things (Telier, 2011: 191). Here, public engagement is not initiated by a company or an institution but by specific communities with a shared value and interest in making.

When systems of engagement are fostered by institutions there needs to be a desire for openness and learning. Van Bekkum et al, (2016) voice their concerns about the promotion of public engagement within liberal agendas for health and medical research. Their scepticism is based on the lack of shared understanding of what it means to engage the public. They state that although the common definition of public engagement is a two-way process of shared listening and interaction with the goal of creating mutual benefit, this is muddied by the term public-facing. By engaging in public-facing activities that provide one-way dissemination, researchers do not need to engage with people collaboratively but instead avoid the complexity of negotiating meaning and retain their role as the expert. In addition, they highlight the differences in the theory and practice of public engagement. Co-design inspires a more specific reading of public engagement. Bowen et al (2013) discuss how participatory design has been used within the National Health Service (henceforth NHS) to develop co-design into the more nuanced 'experience-based design'. This takes into account the "strong professional hierarchies, high degrees of specialisation … and an (understandable) aversion to risk" within the current NHS. By elaborating on patient and staff experiences and personal accounts, this paper aims to show the value and adaptability of co-design. It also shows how the move from collaboration to experience has weakened the ethical underpinning of co-design that aims to flatten hierarchies and promote inclusivity. The people who participated did value the interest in their experiences and opinions, but overall did not feel part of the design process.

In the arts, public engagement is less rigid in its approach to function than design. Social design is often introduced as a way of solving problems or developing strategies and is thus valued based on whether those problems or strategies have evolved or created new paradigms. Speculative designers, such

as Dunne and Raby (2013), have developed design practices that sit closer to the arts in terms of their role in society, as "speculative design depends on dissemination and engagement with a public or expert audience... The usual channels are exhibitions, publications, press and the internet" (p.139). They shift design from problem solving to problem finding, and aim to speculate and provoke design futures. The value of arts and speculative design as a form of engagement is more challenging to situate.

In 2006, the *Arts Council UK* launched its first public enquiry into the purpose and value of the arts. They found that people valued art for a wide range of reasons from life affirmation to spiritual engagement to "a civilising force… that drives society forward and helps people to develop in positive and meaningful ways" (Keaney et al, 2007: 9). By placing art and art production in contexts outside the gallery it can engage people and give voice to issues, communities and practices. The arts also grapple with questions of quality in terms of value; people consider the "quality of the art and quality of the experience … [in creating] art that challenges people" (Keaney et al, 2007: 10). In contrast, although design shares an aesthetic and conceptual underpinning, the quality of these aspects – particularly the need to challenge – is not often considered in discourse around design participation (Lee, 2008: 32) with much of the focus being on the stakeholders and changes made.

At the heart of value and public engagement lie challenging questions about who is able to experience the arts. What form does this experience take? And how can the hierarchies of participation be flattened? The *Arts Council UK* 2007 report found that there were strong differences in opinion, in relation to the use of public money for the arts. Is the role of the arts to challenge through innovative art, to be accessible and reach out beyond traditional boundaries, or to provide specific social benefits like "working with communities, in education and health, and contributing to economic growth and social challenges such as conflict resolution" (Keaney et al, 2007: 12)? Art therapists do seem to fall into the last two categories, but are not typically seen as part of the arts or in applications for Arts Council funding. Moon (2010) argues that, as the arts take on these alternative roles within society, art therapy has a role to play within art and design discourse and can be enriched, in turn, through interdisciplinary conversations.

Art Practice and Art Therapy

Alongside established techniques for exploring grief creatively, for example art therapy, co-design may provide new lenses to approach working collaboratively.

This includes reflecting on the things and data left behind from and about the deceased, considering the affordances of specific materials, and exploring what experiences we want the public to have of them. It allows for the fact that users or participants have a distinct and nuanced knowledge of the issues within their systems, even if they do not know how to tackle them (Sanders and Stappers, 2008). By looking at the way that continuing bonds puts the knowledge and understanding of how to grieve back into the hand of the bereaved, in an individualised way (Ch.1, p.25), it seems that co-design is one method to help inform and give structure to new creative approaches of working with bereavement in a shared but individualised way. As my research has involved art therapists in an active way from three different angles – clinical supervision, practitioner and participant – it is important to understand how the research connects and differs to current practices within the area of art therapy, wellbeing and making.

Materials & Media in Art Therapy: Critical Understandings of Diverse Artistic Vocabularies (Moon, 2010) has been a strong influence within this research, as it is an approach to art therapy that engages strongly with the concept of materiality. This includes how materials can be used for different purposes, modes of investigation, situations, political relations and presentations. Moon identifies the need for linking design and art therapy within a more inclusive form of visual production. She states that the interdisciplinary of visual production is absent from contemporary art therapy literature as there is "almost no mention of design theory or practice" (p.20). The text is novel in its approach to art therapy as it brings together a diverse collection of research that focuses on a wide range of art practices and materials. They are contextually suited to individual groups and take into account the author's understanding of the role of art therapy to help people make sense and critically view the world around them. The studies are also uniquely designed for the communities that engage with them. There is very little mention of psychotherapy literature or specific models that the cases follow but rather they describe an approach to making that is in line with the themes and concerns of this research.

One example for this can be found in the chapter on *Bedouin Woman's embroidery as Female Empowerment* (Huss, 2010: 216 -229). Huss argues that the specific craft of embroidery already being produced by the Bedouin women is used "as a culturally embedded speech act of female power" (p.215). The author aims to complicate what it means to use culturally sensitive materials, so that a western perspective on art production as individualised self-expression does not

undermine it. In addition it critiques the positioning of creativity as distinct from craft or making, claiming that the traditional embroidery creates a unique vocabulary that may be used therapeutically (p.221). It is only when these processes are taken seriously that we can make use of an established or establishing vocabulary of making, which is not widely undertaken within current art therapy practices. In support of constructing a vocabulary through making, Yi (2010: 103–117) negotiates the specific materiality of body adornment for the disabled identity. By making body adornment that uniquely fit to those who are producing them – e.g. two fingered gloves, baby onesies in a range of forms et al – she creates an environment of personal care and reflection on these body parts. She also provokes a wider public conversation around disability, with a collection of photographs labelled "Call me disabled? Look at me again" (p. 107). This combined use of making and framing through textiles and photography explores different points of reflection that are contextualised through making. It mirrors the way I would like to situate my practice within the discourse of bereavement, as functioning both for the participants and as showing an artistic practice from the bereaved that is not framed through a medical, therapeutic or charitable lens.

Aesthetics, Making and Art Therapy

In *Facilitating a 'non-judgmental' skills-based co-design environment*, Glazzard et al (2015) share a process of working with wearable textiles as a medium to understand the relationship between wellbeing and making. They use a person-centred approach (psychotherapy) and co-design to work with an interdisciplinary team, including textile designers, researchers and mental health communities. Through this they facilitate a series of making activates that involve the creation of a range of self-directed e-textiles. Their research focuses on the therapeutic qualities of making by setting up a safe space for people to learn and develop together. It also focuses on the creation of artefacts as an outcome that helps to facilitate confidence, honest conversations and a strong group dynamic. Their aim was to integrate the therapeutic technique of the person-centred approach into the co-design process to explore making as healing. This research is relevant for my reflection on the connection to art therapy and for my understanding of my participants, as they will engage in similar processes of learning, making and exhibiting. However, by removing the therapeutic goal altogether, I believe my research will retain its focus and impact on the design questions, which will ultimately foster a stronger critical reflection. The processes of making that my participants are responding to is also more complex (in terms of what they aim to

achieve through making) than the sessions described in Glazzard et al's article even through it shares many of the same qualities.

To understand the relationship reflected upon between my own research and developments within the wider field of art therapy I consider Lister et al's 2008 article *Current bereavement theory: Implications for art therapy practice*. Within this article they aim to encapsulate the current developments in art therapy that are explored through new theories of bereavement, such as Neimeyer's (2001) approach to meaning construction. Although there is a rejection of specific linear modes of bereavement, such as the stages of bereavement, the approach to meaning making through art remains quite literal. They use materials as metaphors for stories and other cognitive actions. There is no deep exploration of artistic practice, and the examples given use drawing to illustrate situations for talking and thinking through issues and emotions. The materials are put in service of a pre-defined goal of reconstruction or emotional portrayal through drawing, puppetry, clay, collage et al. Although some examples do show a multi-sensory approach through clothing, this is only understood as sensory additions, as part of the methods of collaging or other gathering techniques. A lack of artistic methods is remarked on by Mahony (2010) where she states that art therapy has not developed enough of its own approaches to thinking through bereavement and instead uses many models from other disciplines e.g. psychotherapy and psychoanalysis, which inform the mode of art production used within the sessions. She also critiques the fact that not enough art therapists see art practice or artistic traditions as a key factor within their work. She states that "when art therapists stop making art… their practice becomes more verbally oriented" (Mahony, 2001: 51).

Using Artistic Methods to Create New Practices in Design

Both in Glazzard et al (2015) and Lister et al (2008), there is a focus on making instinctively in short bursts and making with pre-chosen materials and processes. The making in these cases aims to serve a specific function or exists within a space that one accesses. The practice is not being lived with, and this distinguishes it from deeper design or conceptual approaches to making. Mahony (2010) supports this, claiming that "an art based, studio approach … [develops] a complex language of art forms with craft emerging as a significant connection. A full range of media, tools, methods, equipment, materials and environment is required for an expressive and exploratory creative process that may be

generative" (p.269-270). Moon (2016) also examines how this can be more collaboratively approached when material choices are integrated into the process, acknowledging how the homogeneity of material choices in art therapy is often reflective of western values (p.96) and that "working with clients or participants, not on them or even for them" (Moon, 2016: 62) could constitute new ways of deconstructing the power relations and ethics within therapeutic relationships.

My research adds to this discourse by developing a situated process, which focuses on the creation of a final piece. The focus on individual collaborations through co-design is important as concept development is negotiated in a situated way and discussed in terms of qualities, suitability, aesthetics and feeling. Merewether (2006) in *The Archive* describes this subtle shift as "art's potential to open up a world beyond an empirical or manifest order of knowledge" (p.14) and it is this quality that contrasts it to a process that is instigated and evaluated through therapeutic aims. My previous reflections (Ch.2, p.55) on archives and collections show how design processes may be used to develop experiences that promote thinking and feeling through things. These processes move from being verbally oriented to tactile, as they approach making in a way that organically grows into design concepts, informing the creation of artefacts.

This process of organic making challenged the team of art therapists I recruited, as it was quite different from their previous experiences of practice. This was particularly true for those who identified themselves predominantly as therapists as opposed to artists. In a meeting[68] during the recruitment phase such concerns emerged. One of the anxieties expressed was that the art therapists felt that having to produce collaborative works that would be exhibited as part of the practice research would make people view them as artists and expose certain vulnerabilities about their status, role and making skills (this is further explored in the evaluation, Ch.5, p.135). Moon (2016) challenges the art therapist's reticence in taking on the label of artist, claiming that it undermines the credibility of the field. She states that "by disowning the identity of artist, art therapists trivialise and undercut the progress being made in the wider world by those who challenge art world hierarchies and embrace a more inclusive, accessible and participatory concept of art and artists" (Moon, 2016: 59). In addition to this, Kapitan (2011) considers why craft has been omitted in most art therapy practice, stating that

---

[68] This meeting of my recruited team of art therapists took place after a British Association of Art Therapists (BAAT) meeting called *Creative Response* on the 11th October 2014. At this stage five art therapists were in attendance.

fine art education is exposing this discipline to a material and process bias that conforms to the narrow market demands of the art world (p.95).

However, although Moon sees it as a political statement to take on the label of artist and Kapitan sees craft as a way of opening up beyond the art world, as a designer I see the process as an instigation of inquiry around function. What then is the function of the artefacts being produced, and how does their position in the gallery position them in the world? And what does it mean to interpret them in terms of design? Through craft and crafting, stories and people are being made materially, and although they are positioned in the gallery they sit beyond commercial or problem solving tasks traditionally attributed to design. Through integrating and translating the things that define their loved ones, the exhibition aims to give the experience of feeling with the artefacts through textures and glimpses of stories.

Another point that produced much debate when mentioned to the team of art therapists was the fact that I was not going to record the sessions. As art therapy is defined by language associated with psychotherapy, the sessions are traditionally recorded so that notes can be made and progress mapped. It appeared to shock my colleagues that I was willing to lose this integral part of their practice. As a designer however, our recording process is normally a sketchbook in which we collect ideas, iterations, sketches, observations, research, aesthetics et al. This form of recording inspires a different mode of research and is not necessarily about capturing and interpreting but rather distilling and building upon. In *The Reflective Practitioner*, Schon (1983) discusses the similarities between design and therapeutic practice through the reflection-in-action of students with supervisors or teachers. This in-tune negotiation of learning professionals is applied to the reframing of design or psychological issues in a similarly situated way, where the material sketch or words from the therapy session are considered through the reinterpretations of the supervisor in collaboration with the student.

As my research engages with the participants as collaborators and co-designers as opposed to clients, the boundaries in timing are not as clearly defined as they would be within an art therapy session. It is important that, if someone needs to e-mail you to get some feedback on an idea they have just had, they are able to do so. This helps the fluid development of the process. There is also a much wider range of communication methods used such as: e-mails, SMS, Skype and

physical visits to the hospice and people's houses. These help to form the collaboration, the means by which can take place through trust and co-operation.

Crafting as a Flexible and Emergent Process

In order to achieve flexibility as discussed but still retain enough structure for the sessions to work, this research uses crafting as defined by McCullough (1996). He considers crafting as a flexible and emergent process of selecting and combing materials and practices through the tacit knowledge[69] and the skill of the maker. Richardson (2005) extends this in his "consideration of craft in terms of attitude toward material, humanity, and environment" (p.157). He applies this with a comparison of digital and physical artefacts and concludes that a proficiency in digital systems and the ethics around it allows the digital to be crafted. Jucucci (2004) comes to the same integration of digital and physical things but from a performative perspective. This commitment to a deeper understanding of materials, within a specific environment or frame creates proficiency, which may apply as much to joinery as to coding. This research uses crafting as a method to situate the design lenses described in Chapter 2 (p.69). These lenses are used within the process to focus on particular aspects of the practice. By considering what features **structure** the collection, how we want to **embody** the person within the collection, which **mediums** will we use to construct and make with, how we can use supporting mediums such a sound, words ect to **animate** or transport people within these collections and what experience we want people to access by **containing** these collections within the final piece. As a process, crafting can make with digital and physical things but must also make with the knowledge of the bereaved, which is core to the conceptual development. The ability of both individuals, participant and practitioner, to rely on the tacit judgements and concepts occurring through natural conversation and making is what drives this creative collaboration.

In *Design Things* Telier (2011) describes this succinctly by stating that the design process works in a "'meandering way', with 'floating concepts,' while maintaining things at different stages of incompletion" (p.21). This meandering is crucial within this project, as we enact a process of sensitively pulling at the entanglement of people with data, documents, traces, objects, collections and archives, in order to put them back together in new ways that support a critical

---

[69] Michael Polanyi defined tacit knowledge in *The Tacit Dimension*. Tacit knowing refers to the things we know but cannot explain how or why we know them, it also corresponds to design practice as an intuitive approach whereby "the things that we know… [include] problems and hunches, physiognomies and skills, the use of tools, probes and denotative language … all the way to include primitive knowledge of eternal objects perceived by our senses.". Polanyi, M., 1966. *The Tacit Dimension*. Garden City, NY: Doubleday.

consideration of their meaning. This emphasis on individual collaboration, conversation and understanding helps to develop an approach to the archive whereby there is no fixed process or outcome. Instead, throughout the process, the practitioner views the different forms of data being discussed as raw material with a range of unfixed potentials (Alfondy, 2007). It also aims to question the separation of physical and digital legacies (Boomen, 2009) and to consider whether aspects of crafting, narrative and curation can aid in drawing these collections together. These collections offer a plurality of narratives, experiences and aesthetics, which have the potential to give a wider scope for reflecting on that person's life and death. This is further supported by Telier's view that we should "not seek to 'model' the design process or to direct our attention to particular tasks, techniques, or design strategies (such as problem solving) but rather focus on particular 'qualities' of the environment of space and artefacts in which design takes place" (Telier, 2011: 25). This works in practice when collaborating with the bereaved, who may or may not have prior experience of creative practice, by mixing this flexibility in process with a focus on producing artefacts for a final exhibition as a core objective of the research.

In *All This Useless Beauty: The Case for Craft Practice in Design For a Digital Age*, Wallace and Press (2004) argue that beauty through craft, where craft is defined as a unique form of making, plays a vital role in humanising technology. They reflect on Dewey's description of beauty as an emotion and extend this to the experiential, in terms of the relationship we build with crafted objects that possess qualities of intimacy, beauty and sensitivity. They contrast this to manufactured design objects that don't possess the same qualities due to the distancing of the designer to the object being made through "engineering, marketing, and all the other specialisms involved in bringing that object into being." Through crafting the artefact emerges from an intimate relationship between the maker and their material, and creates a bond through labour. By using craft in relation to loss this intimate relationship and labour can be used as a mode of thinking, both about the intimacies in relation to the person you have lost but also in the material you are working with. This can be seen within the participation, with Sam's dedication to creating hundreds of felt mushrooms for Charley (App.3, p.200) with millions of tiny incisions.

Developing the Materiality out of a Collection

By enacting a process of making, design shifts structures. It creates fluid possibilities through changing environments and shifting the way that people

engage with them. However, designers do not always show an understanding of the structures they intervene in by creating new things. Kimbell (2009) charts the struggle between designers and the things they create, including the separation that is created when designers move from making towards design thinking. These conflicts in design stem from whether you focus on an understanding of people's relationship to things or on things in terms of their processes of construction. Bringing together these two aspects has created design research, which focuses on the deep analysis of specific situations (Simonsen et al, 2014) or communities (Jones, 2014) and introduction of cultural probes (Gaver et al, 1999) and prototypes (Odem et al, 2012; Moncur et al, 2015) for people to live with. In the case of cultural probes and prototypes the designers are exploring the combination of these two modes of inquiry by making things and taking the position of observing the things in use. They have specific occasions of entering and exiting the site, performing actions such as interviewing, deploying probes, making, deploying prototypes and documenting. In the foreword of *Situated Design Methods* (2014) Friedman and Stolterman claim that one of the challenges for the convergence of design practice and research are the "increasingly ambiguous boundaries between artifacts, structure and process." (Friedman and Stolterman, 2014: viii)

This research is situated within these boundaries; it slips between artefacts, structures, processes and people. These are difficult to distinguish or discuss independently, as the artefacts function through their production and re-structure people and environments as they are being made. By creating a home studio, the home is shifted. The creation of artefacts also creates people. It identifies the role of the dead but also makes solid the emerging identity of the person without the other. Design and observation must also be distinguished. By taking a personally situated and emergent approach to being part of these sites and collaborative partnerships, the boundaries within the research become porous. Research both frames the process but is also drawn into the process. Through the collaboration I am looking for the unexpected and reflecting-in-action on what is being produced (Schön, 1982). This often contradicts the expectation of the research but allows for natural shifts in the way research questions are articulated and responded to (Barrett and Bolt, 2014). By flipping the approach to enquiry and focusing on live action rather then documentation, this research learns from people rather than about them (Ingold, 2010) and invites them to be collaborators and co-creators (Rubin, 2016) of the research.

The research findings develop in an emergent way that uses immersion to create "'unpredictable attentiveness' allowing for a 'transformation of perspectives' that moves slowly over time" (Gunaratnam, 2009: 13). This creates an environment for the researcher to reframe the research based on their continual learning from situated practice. In *Making* Ingold (2013) looks to the fields of anthropology, archaeology, art and architecture to create new modes of inquiry that deconstruct artefacts, structures, processes and people in a range of practices. He explains that this interdisciplinary approach is not a random collection of practices, but an edited selection of processes that share a common approach to inquiry. They allow for different ways of knowing about people and places. He uses this collection of blended techniques to understand the context and learning that may be taken from specific sites or methods of production e.g. field notes, sketching, architectural drawing, basket weaving et al (p.22–24). This forms a more complete picture and creates a diversity of perspectives that reveal glimpses of the whole. This diversity in thinking allows sense to emerge from complexity. Jefferies (2012) states that "practice can be understood primarily as the knowledge, tacit or otherwise, of how something is done within… dynamic systems of complexity and emergence" (p.76). This approach to practice research allows research questions to be negotiated and carried throughout the practice but not finalised until the practice is completed.

In the context of bereavement, pain is a good example to discuss as it transcends many attempts to pin it down or theoretically define it. The individualised understanding of bereavement is important and is being reflected in some forms of therapy, particularly constructivist approaches (Ch.1, p.27) but we must also consider how different modes of inquiry allow for closer examinations and experiences of pain and loss. Gunaratnam (2007) discusses how her practice of constructing art and poems from her interviews responds to pain in a different way to traditional modes of research. To see the people she interviews in this way creates an emotional and sensual response, which is ethically situated and corporally felt. It is in this way that she transcends the role of observer and explores how knowledge may be constructed through felt experience. This interdisciplinary approach to crafting as a process also reflects how "funeral celebrants have been taught to hear and edit mourners' stories in particular ways… to make a readable story." (Walter, 2009: 144) The techniques that celebrants use stem from knowledge of contemporary approaches to bereavement (Ch.1, p.30) but differ in their creative application of these techniques. The training of funeral celebrants is also of importance here. The interview process used within the construction of the funeral allows the celebrant

to publicly perform their integration of narratives from the family in order to create a more synchronous story of the deceased's life (Walter, 2009: 63).

Through making we can produce a different kind of talking, there is collaboration between words, movement, materials and focus. Ingold (2013) uses the examples of his four A[70] of collaboration, stating that, when descriptions could not develop the understanding necessary to align the disciplines, they needed to do things as a group. These things included weaving, making pots, rebuilding a drystone wall, polysonic singing and so on. It shifted the conversation. The relationship between making and talking through studio practice techniques, applied within the home, is one that has become important within my research. As we move from a space of talking to one of making, we shift the conversation from speaking about the dead to making with the dead, as an informing principle through which the emergent art forms. For Ingold (p.31) making is a relationship with materials rather then a person's will imposed on them, and it is perhaps for this reason that my participants have all chosen to work with some form of craft as material process e.g. clay, felt and textured paint, which can be practised within the home.

Ingold's interdisciplinary approach to research also explores different forms of knowledge production that are placed on an equal level. He asserts that craftspeople are 'thinking through making', while theorists are 'making through thinking'. The collaboration of these two modes of thinking is reflected by De Waal (2011) who asserts that the reason why he as a ceramicist chose to write *The Hare With the Amber Eye*s (Ch.2, p.65) is linked to his own understanding of practice and the connection between theory and practice.

> "How objects get handled, used and handed on is not just a mildly interesting question for me. It is my question. I have made many, many thousands of pots… I can remember the weight and the balance of a pot, how its surface works with its volume… I can see how it works with the objects that sit nearby. How it displaces a small part of the world around it" (De Waal, 2011: 16)

In this extract De Waal is considering himself as a craftsman and a researcher. The biographical approach to his research is expanded by the fact that he also finds a function for the story in constructing a deeper understanding of his own approach to ceramics and making. This includes the network that making a pot

---

[70] The four A are Anthropology, Archaeology, Art and Architecture.

inspires and a consideration of how or to whom they may be passed on. The materiality of the story is referred to when De Waal describes that, through his own retelling, the story is 'thinning' (p.17) as one might imagine an overworked pot collapsing on the pottery wheel. When reflecting on how these objects survived while so many died in the Holocaust he proclaims "I cannot bare for it to slip into symbolism... These stories unravel me" (p.283). The felt experiences of the stories are literally unravelling him. His identity as a person has been shifted. This consolidation of tragic events from the past has become his story. Because he is part of the story, his own biographic details are entwined within the process of collecting. He moves the reader through the remnants of the archive and his feelings and desire for a true authentic record. By labouring over documents in four countries, he is able to construct and provide care for his family's history. For this small period of time, a contained time of researching and writing the novel, De Waal has replaced the materiality of clay – wet and flaking as it dries – with his fingers being "tacky from old papers and from dust" (p.345).

Design, Materiality and Meaning

Ingold (2013) promotes this materiality through the lens of interdisciplinary research, claiming that by not focusing on finished objects or works of art as something to be analysed for their social relations and symbolic value creates a different understanding of the creative processes that give rise to them. He suggests that anthropology could regard "artwork as a result of something like an anthropological research, rather than an object of such research?" (Ingold, 2013:8). It is this identification of art production as an objective of research that is relevant to this practice research, as it defines making as a key aspect of the sessions and exhibiting as a logical end to this research. Experimental methods (Schlesinger, 2015) are also important to this approach to research, whereby new knowledge needs to be quickly integrated into the process and negotiated through practice. By using models of studio practice (Telier, 2011) and evaluating the research through narrative, it can be explored not only as an activity of producing knowledge but as a practice which produces a range of outcomes through making with and listening to people (Vines et al, 2013).

Margit Neisig (2014) describes this use of design methods in new contexts as a form of translation, which initiates new networks and involves the negotiation between human and non-human actors to establish new common meanings. The introduction of Actor Network Theory (Ch.1, p.33; Ch.2, p.40) also helps to define the significance of the archive as an active participant within this research,

including its unique materiality or what it is predominantly made of e.g. writing, photography, music, audio recordings, books et al. Other actors include: the participant, the practitioner and the content of the home (as a situated environment), as well as the deceased[71] – as it is a negotiation and conversation about this person that creates a network. This evokes a particular discussion of the materials and things as specific triggers and stories to be formed as material. In the introduction to the edited volume *Materiality* Daniel Miller (2005) advocates this stating that the world should be seen as a fusion of peoples, objects and environments that "transcend the dualism of subjects and objects." By endorsing Latour and Gell's call that there needs to be a greater emphasis on the nature of agency and the need to show that the things we make, make people (p.38) complicates our own understanding of subjectivity[72]. It is through this lens of making that this research aims to contribute as a way of complicating the subjectivity of the deceased through a network of creative interventions, drawing different nodes together with the aim of creating new forms of meaning.

Participants' Desire to be Hands on with Making

The affordances of the digital that are being worked with here are its ability to amalgamate with material forms of craft and to be presented as an exact copy that works with features of time, kinetics, structure and randomness (McCullough, 1998). Using a range of senses was something that was also often discussed within the sessions, with sound, smell, light and movement all being features that could be added to the crafted pieces. The participant's choices of craft – felt, textured paint, clay – all engage very strongly with touch and feeling, adding to the multi-sensory quality of the pieces. Telier (2011) claims that this is core to the act of designing. The participants are engaged with:

> "bringing forth something that does not exist through material transformations and communicative acts involving design artifacts. Artifacts can be seen as 'multimodal texts,' as they address different senses and modalities of communication." (Telier, 2011: 105)

The desire to engage in making with the senses shows a commitment to preserving the multiple 'registers of life' (Back & Puwar, 2013: 29), by creating

---

[71] It must be noted that we only become an expert in the deceased from the bereaved's perspective, therefore it is not the deceased themselves that we know but we help to make tangible their durable biography.

[72] This movement also reflects key writings around Posthumanism and the call to open up the human subject, creating fluid boundaries between people, environments and technologies, as discussed by Katherine Hayles (1999) in her book *How We Became Posthuman*. This has been reflected in relation to digital death within the article: Pitsillides, S,. and Jefferies, J. (2013) 'Narrating the Digital: The Evolving Memento Mori'. In *Digital Legacy and Interaction*, Maciel, C,. and Pereira, V,. C,. (eds) p. 83-99. Springer International Publishing.

things that have an agency. By incorporating the qualities of the dead, including their environments, it gives people who did not know them the experience of engaging with them. This is something that was also felt within the collaboration. An example of this would be the smell of the forest in Sam's work. This was something we discussed in the early stages of concept development. However it was through the commitment to authenticity that the smell was rejected from Sam's work due to the difficulty of reproducing or constructing smells that truly reflect environments (App.3, p.200).

How Being in the Home Impacts what is Produced

The use of the particpant's home within the research provides strong support of familiar surroundings, helping them to feel comfortable and in control of when sessions are scheduled (Glazzard et al, 2015). It also establishes the home environment as an impromptu studio. This creates a safe space for them to work in and allows a continuation of flow after the practitioner leaves, allowing them to create crafting spaces that can be assembled and removed from within the home. As the collaborations have a duration of between 23 – 28 months, around 2 years, they require an in-tuned approach to working with people on a long-term basis. This is enacted not only through making but also though sketching, listening, writing, taking field notes, photography, telecommunication and live presence (Back and Puwar, 2013).
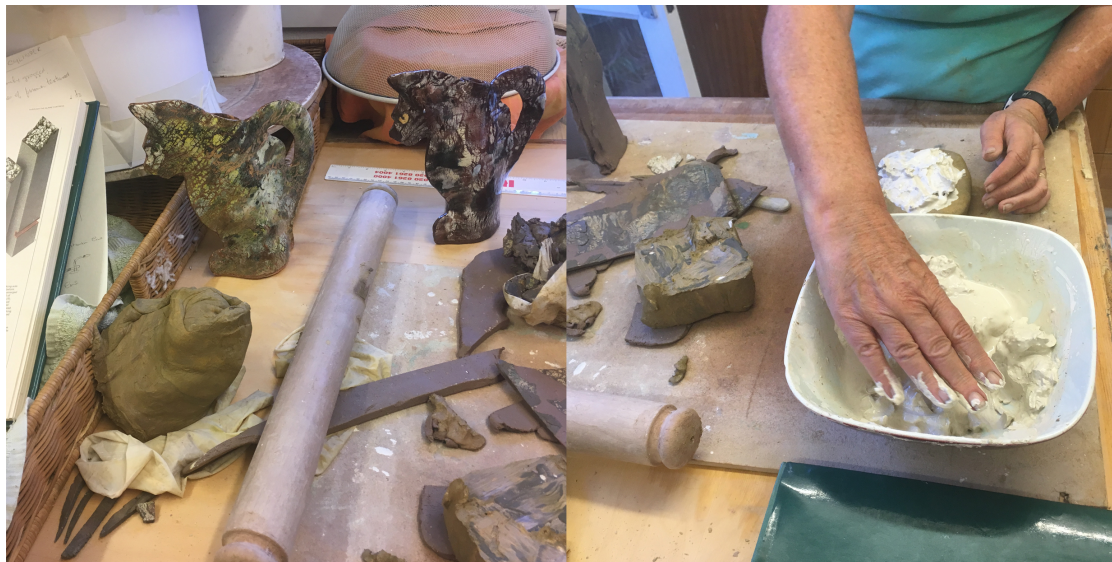
Figure 13: Freda's kitchen set up as her home studio for working with the clay and enough surface area for hand building.

This diverse range of activities in their amalgamation constitutes design events (Telier, 2011: 107) in the emergent form of the artefacts. In the wider site of

Berkhamsted, unknown to me prior to this research, are the more individualised sites of Freda, Sam and Anne's homes. Although the level of design experience within the group varied, Cross (2006) asserts that the organisation and aesthetic choices within the spaces we inhabit show people's natural design ability, even if this is confined to the placement and collection of specific kinds of designed things. Therefore the home, as a specific environment responds to the 'creative density', which Telier (2011) considers as the inspiration that can be found "for odd, surprising, or useless objects in the studio" (p.34). Interesting combinations of these things can push forward the conceptual development. This also helps the craft to continue existing in the edges of peoples lives and allows participants to be flexible about when and how they work on their artefacts.

Although it is important that this research is situated in the home, it must also be understood through 'multiple partial perspectives' (Suchman, 2002) that show how various forms of communication inform the collaboration that emerged. This wide range of artefacts from sketches to e-mails, produced and evolved from the sessions themselves, are folded back into the process. They are not a product of documentation but instead form a part of maintaining a flexible design space (Telier, 2011: 108). These homes become small studios for the duration of the research; in them concepts are developed, materials are discussed and worked with, technical issues are considered and planned for, and artefacts begin to solidify.

Once the studio is set up in the home there is also the challenge of building the confidence to exhibit and show the work to the public. This involves making the sometimes deeply private public and questioning who will see the work. How will they perceive it? What experience do I want people to have? These question begin to frame the artefacts being produced and define how they are conceived of, in terms of the gallery at Stockwell Street in Greenwich where the exhibition takes place in February 2017.

A visit to the gallery on the 9th July 2016 solidified some of these concerns. Discussions between us moved between technical questions, spatial considerations and the experiences that we wanted to evoke. This was particularly true in relation to a sonic element of one of the pieces by Anne. It would include digital music produced by the deceased and their voice. As the piece becomes public there is a wider custodian role of the participant with concerns like how shocking it would be to family members if they approached the exhibition and heard these evocative sound pieces. This has been approached as

a creative challenge, where levels of restriction, use of headphones or downloading the more sensitive sound clips were explored as layers of experience. These could provide different vantage points for public and family members. The exhibition adds another level of assembly, narration and environment to the artefacts, as the participants begin to consider that they are indeed making for a public forum. It includes giving the work to a new audience and moving from private to the public and thus closing the design cycle.

The Sessions: From Narration to Curation

This section will review the process of working with participants from narration to the beginning of curation. My field notes from sessions with Freda will form the basis of this section and will be used to reflect on the methodologies and approaches discussed in previous sections. It is important to note that Freda's story will frame this deeper discussion of the breakdown of process, which will then be discussed in contrast to Sam's and Anne's reflective interviews within the evaluation (Ch.5, p.128).

I met Freda at the St Francis coffee morning on the 31st October 2014, shortly after the death of her husband Victor. As I described the project to her she showed me the Funeral Announcement Card that she carried around in her wallet. On the back it had a collage of images of Victor with butterflies in between which was a symbol that flittered across his funeral adorning the coffin and flowers.

Figure 14: Victor's coffin adorned with butterflies and other hand painted details from Freda.

"[This coffin] arose from one of the sessions of an end of life course for carers at St Francis. This particular one was by Justin Burgess of JJ Burgess and that was where I heard of cardboard coffins which you can decorate yourself. I and a group of our friends and helpers got a great deal of comfort in what we saw as a last gift to Victor."

(Extract from e-mail, 6th March 2015)

This extract shows how Freda was already predisposed to exploring Victor's life and death in a creative way. It was supported by the hospice's interest in creative bereavement and situates my research well within this environment. Freda's involvement in the many activities within the hospice, including the volunteer's network, also helped to build the trust for collaboration. In line with her previous experience and her background as a ceramist, Freda was able to understand the project and identified with the material approach to crafting the archive. As someone who is an active maker she showed an openness to sharing that has provided fertile ground for this research.

Narrating the Archive

"When I enter Freda's house I am immediately struck by the materiality of it and the sheer amount of books, ceramics and other possessions that are piled, ordered and displayed in the various rooms. We go upstairs to a tiny study which houses a wealth of files [documents], books and a 'HANNSG' computer, which I am told was the replacement for a beloved Amstrad.

This is where I truly begin to become acquainted with Victor."

(Extract from field notes with Freda, 31st January 2015)

Talking about Victor's relationship to the two computers in his life begins to set them into a kind of fluid structure; they are easy to sort into mental categories, one he loved and the other he tolerated. It is in this way that the things are recognised as 'matters of concern' (Latour, 2008). The fact that one computer (Amstrad) is no longer there but held much value and that this has been replaced by a new computer (HANNSG) that holds little value, but performs the important task of reading the floppy disks from its predecessor, shows the agency of things that we are to recognise through the specific function they currently play. Through interacting with things we uncover their nature. This includes the fact that not all writing is of equal value or meaning – the same is true of all of the

books and documents within the small office. We consider the books he bought just before he died; the Iliad and Odyssey, two great adventures that he had no opportunity to read due to the deterioration of his vision, function as part of the narrative of his decline.

Through this process of critical reflection and narration we are able to drill down to why each thing matters and how it contributes to Victor's life story and Freda's own understanding of him. The process of narration becomes complicated in the combination of selecting things from the shelf or accessing them on the computer. What we discuss and the way we discuss it defines this sense of hierarchy and puts the things into their place in Freda's mind. Telier through a design lens claims that this experience of things contributes to the complexity of designing them, where "social experience and interactions [of articulation] continuously transform these objects without canceling the traces of previous representations" (Telier, 2011: 56). It is in this way that articulation causes a form of thinking through things or mental 'bricolage' (Turkle, 2011) – once we interact with it the collection is more than its contents. They are assemblages of sediment that grow in layers of narrative embodying the collection and framing its function.

It is these connection points that are the beginning of conceptual development. This biography through things forms a very different biography than is constructed through the range of practices previously discussed either from celebrants (Walter, 2009) or bereavement theorists (Neimeyer, 2001), narrative researchers (Gunaratnam and Oliviere, 2009) or even art therapists (Lister et al, 2008). The home office acts as a situated environment (Suchman, 2002) that affects the way we access his things and how we engage with them. Beginning with the obvious and reachable and then moving spatially through the files, boxes and books, pulled down from the highest shelves and examined for their contents. Once the process had started and we were in our flow nothing was safe from our enquiry and our discussions were rich and emotional.

Getting to Know the Deceased

It was enjoyable to listen to her stories of the past and the way the relationship between Freda and Victor had grown. This genuine enjoyment and listening also helped Freda and me in levelling the collaboration and stimulating the stories to keep being told, allowing us to spend three happy hours going through Victor's office. Here, narrative is used as a tool or process within the research. During the story-telling the researcher is reflective and passive (Gunaratnam, 2009: 55) and

this helps shift the power balance building confidence over time (McGuinness, 2016). Talking is also used as a way of getting through the layers of who the person was, through taking an interest in their things is "one of the most challenging, but vital skills for a narrative researcher… to 'go with the flow'; to allow the gestalt to emerge in its own way – and without interruption" (Gunaratnam, 2009: 50). Freda seems to be more at ease talking about Victor through his things than organising them or beginning to edit them. She mentioned that she had not tidied his office yet and that this was simply due to lack of time, but it seems as we move through the space there is very little desire to get rid of any of the things that are so entangled with Victor's life. Being in the office, it is hard to say where Victor ends and his things begin, even the books he has not written are bound by the structure of the office and work in the service of embodying Victor for me, the listener. He is constructed in such a detailed and careful way that I feel like I know him, and when I check my understanding of certain stories with Freda she confirms my understanding of him, which builds her trust in the collaboration.

As Victor had died over a period of 8 years, Freda, although quite recently widowed, did not appear to experience a great deal of deep emotional turmoil in participating in the research (one exception of this was the one year anniversary of his death). She had acknowledged his death and as his primary carer had watched his slow degeneration and loss of some of the characteristics that made him her husband. She also observed that he gained new characteristics during his illness, such as openness to contact and being touched. In the early stages of design development Freda had been interested in documenting his change over the process of his illness and these shifts in character and ability, but as time progressed the idea distilled to a singular piece that would encapsulate his life.

As we enquire into each thing the collection of floppy disks emerge as a particular point of interest. Firstly Freda is not sure if they will still work and secondly she does not know what they contain. As the machine whirrs and takes its time, we think we may have to abandon this outmoded collection – but suddenly they just open. Mostly they are Victor's writing from his old Amstrad but it is always a surprise when the specific contents of a disk are revealed. This spontaneous discovery (Banks, 2011) is one of the properties of digital things that can be used later on within the process and adds to the delight when something significant is uncovered.

"Inside the floppy disks that we access are a range of short stories and a book… These have also been printed and exist in the room in hard copy… [which we locate for comparison. Freda] is caressing the pages and says that she liked the story better before his edits, that he edited out the humor."

(Extract from field notes with Freda, 31st January 2015)

As Freda touches the book, she is also getting back in touch with it and remembering why it is there. Through her narration of the book she plays with her view of her husband, humanising him by telling the story of how he edited out the humour and asserting her role as an editor and critique of his writing. The discovery of this book is clearly significant for Freda and she gets in touch with me via e-mail before the next session with some comments.

"I have read his book again since you came and found a very interesting insight into how early this supposedly late-onset disease started. Also some insights into a young man two years before we met which I did not understand when I last read it 30 years ago."

(Extract from e-mail, 25th May 2015)

This book, written by Victor, may be examined as an external record of his life. It is semi-autobiographical and in this sense reminds me of Barthes (1981) developing his understanding of his mother through the particular photograph of her as a child (Ch.2, p.64). Freda identifies, through engaging the book in this process, two key additions to her own understanding of Victor's biography. One that complicates her understanding of the development of his illness, which can only be understood in retrospect and not at the time of writing, and one about who he was and how he saw himself two years before they met. From this narration and reflection we are able to begin to distil the qualities that emerge from all the things by creating a collection of words that describe Victor's approach to life. These words are *structure*, *patterns*, *tables*, *code*, and *etymology*. They were drawn from examples discussed within the first session and respond to Victor's interest in shunting tracks of trains and his etymology charts that explored how words had evolved within Welsh, French and Latin. These words are not assigned as metaphors for specific events or characteristics but are used to help guide the conceptual development of the artefact, where "narrativity" may be considered as a

design quality (Tellier, 2011: 67). In addition to this we discussed his professional career as a bureauocrat in the Greater London Council, a writer for The Economist magazine and the mayor of Berkhamsted.

Sharing Inspiration from other Artists and Designers

From words we moved to materials. What materials should we explore Victor with? We discussed the fact that his materiality was one of writing and words whereas Freda's was clearly clay. It seemed apparent that their lives were so intertwined, as he died over a period of eight years, that the object made should be a combination of these two materials. This deep connection of materialities reflects the previous section's approach to design, it acted as a 'floating concept' until it was identified (Simonsen, 2014). Another important stage in the development process was to discuss the work of artists and designers that have explored similar themes and aesthetics relating to our key words. Structure, patterns and tables made me immediately think of the Oulipo group and Raymond Queneau's *One hundred million million poems* (1961)[73].
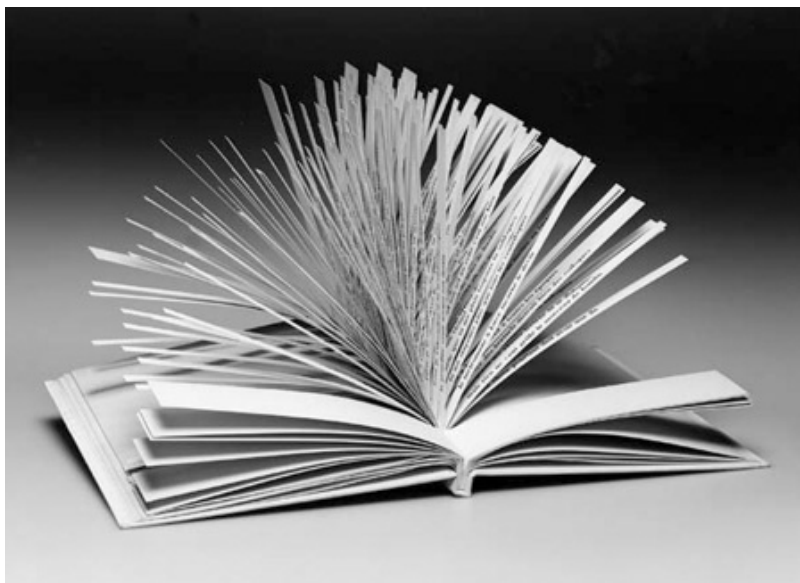
Figure 15: *One hundred million million poems*, Raymond Queneau (1961). Image attribution: Thomas Guest (2008). License: https://creativecommons.org/licenses/by/2.0/ [Accessed: 30th September 2016]

This piece speaks to Victor's love of patterns and his nature as a wordsmith. It also held more then it appeared to, through the remix of poetry lines. It is based

---

[73] An interactive version of *One hundred million million poems* in English and French may be found here: http://www.bevrowe.info/Queneau/QueneauRandom_v4.html [Accessed: 25th September 2016]

on algorithmic structure that could be considered through the materiality of the digital.
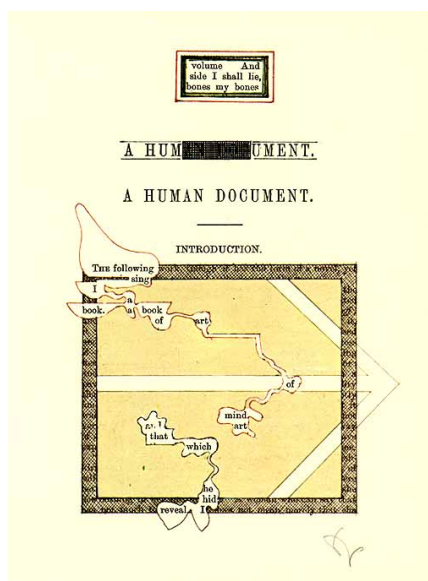
Figure 16: *A Humument: A treated Victorian novel*, Tom Philips (1970) is an altered book created using W H Mallock's 1892 novel *A Human Document* whose title results from partially obscuring the original title: A Hum~~an~~ do~~c~~ument.

With *Humument*[74], Philips (1970) also connected to our understanding of Victor as a bureaucrat who was able to weave stories in the documents that others could not understand. A *Humument* signalled code, patterns and structure, as the original document was altered to convey a new narrative in much the same way that Freda was approaching this process of re-narrating Victors life. Drawing machines like the harmonograph[75] were also discussed as they produce structure and patterns through movement, and we were interested in whether we could have different inputs and outputs at one stage so the things could be literally translated. At this early stage in the process Freda's instinct was to move in the more illustrative gathering, which although beautifully conceived remains as an edited collection.

> "I have been thinking of what to do myself and at the moment I like the idea of a thick book using very thin porcelain paper clay printed with some of Victors short stories and poems, the edges would be cut to a profile like a portrait and the book opened to give a three dimensional head."

> (Extract from e-mail, 6th March 2015)

---

[74] See http://www.tomphillips.co.uk/humument for imagery and further details. [Accessed: 30th September 2016].
[75] A harmonograph is a mechanical drawing machine, which uses pendulums to create geometric imagery. They were originally invented in 1844 by a Scottish mathematician Hugh Blackburn http://www.karlsims.com/harmonograph/ [Accessed: 30th September 2016].

If the process had been shorter or more strictly defined to making or therapy, the porcelain book would have been the outcome and we would not have continued to explore or push ourselves beyond the boundaries of an edited collection, into territories of using collections to craft an artefact that contains or embodies Victor.

Making and Refining

As we looked for inspiration beyond the art world and in the home again, we discovered a collection of train books in the lounge room as documented in the images below. We saw it and it just clicked: from the pattern of the geological mountain; to the shunting tracks that structured and created millions of train paths; to the tunnel carved out of the mountain like the *Humument*, a human intervention to this natural form. It seemed right, and we began sketching a large ceramic mountain and to think about how the words feature within it, whether through sound, projection, ceramic or another material.

Figure 17: One of Victor's train books that we found that shows a cut out of the mountain range and shunting tracks that inspired our design process.

Following on from this breakthrough I received an e-mail from Freda with the subject line "Digital Heritage":

> "I have been thinking this fine morning. Since trains in one form or another were important in Victor's life from the days during the war when he and his friends trainspotted at Preston Road station right through till he watched Michael Portillo's Great British railway Journeys when he was at the end of his life I am thinking of going with this idea. Here are rough notes. – more or less in chronological order."

(Extract from E-mail, 29th June 2015)

It was in this way that participation naturally grew into collaboration. The process evolved organically with both of us able to chip in and build on the concept of the

train, embedding it into the process. From this our sketching began to take shape and we understood how the mountain would tell the story of Victor's life by exchanging the train for words rushing around the mountain. Freda sketched out a ceramic mountain (below) which would have a projector inside with a word train running through it, filled with a collection of quotes from Victor's writing. It is not that the trains are a symbol or sign for Victor, instead they are a frame for his life which can be narrated through both his engagement with and love for trains (Miller, 2010). The fact that the trains contain his stories contextualises them with content, as Freda's ceramic mountain does with the detail of her clay.
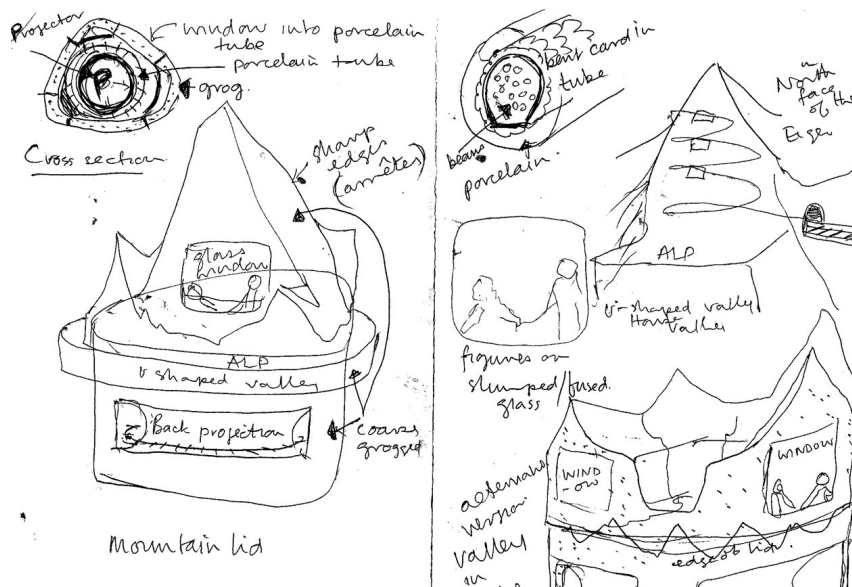
Figure 18: The first detailed sketch of a ceramic mountain with word train.

Materiality and Technology

"The geology of the Swiss mountains is very complex where the rocks which were at the bottom of the Mediterranean before they were crushed and folded up against the ancient rocks of Europe by the continent of Africa moving north are now piled in a huge crumpled mass. Most of the rocks are limestone with pockets of granite where the rocks split and allowed molten rock from below to fill the spaces. [The clay trials] probably need to be paler both for accuracy and for the aesthetics."

(Extract from e-mail, 8th December 2015)

Freda's attention to detail within this e-mail shows how she is attempting to instil the qualities of the Swiss mountain in her clay. This is not a process of illustrating the mountain or interpreting it in a nostalgic way from memory but about

integrating it, as best she can, into the materiality of her physical experiments and iterations with clay. The care that is taken to produce the granular effect of years of layering and the entangled nature of the Swiss mountains is considered deeply. This is in tune with Latour's (2004) reflections about complicating objects to construct things, where he states that talking about a rock is very different to talking about dolomite[76]. The dolomite is "so beautifully complex and entangled that it resists being treated as a matter of fact... [and] can be described as a gathering" (p.159). The Swiss mountains are also beautifully entangled in Freda's and Victor's lives. By paying attention to their geology Freda can reflect on the sedimentation of years of marriage where the clay is active in gathering her thoughts and the geology is significant in its specificity. It must be right or the material story of the mountain will become 'thin', referring back to De Waal (Ch.2, p.65). The materials themselves have agency, and by mixing clays you also run the risk of unexpected cracks and splits. This required test samples to be made and used to test their durability.
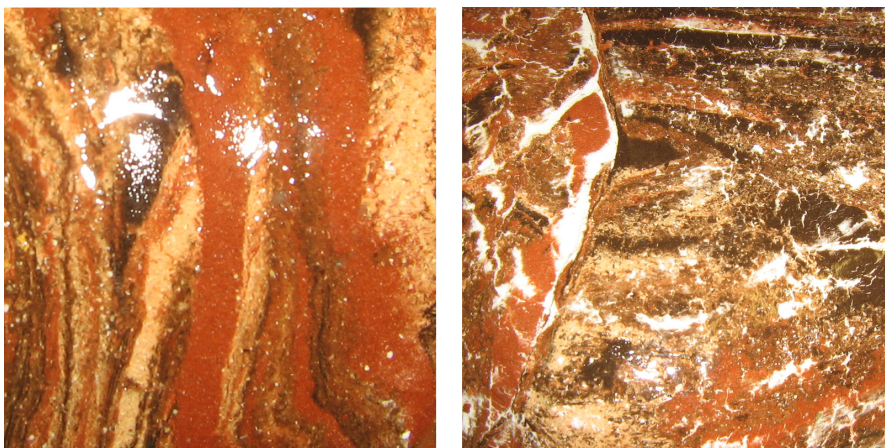
Figure 19: Clay samples, which have been made as bowls and tested within the household.

The scale of the mountain was informed by the size of the smallest projector we could acquire that could spin on an axis and not overheat in addition to the size of Freda's kiln. As Bolt (2012) states her "preconceived notions about the relation between lights, form and knowledge were enabled by a movement from logical rational thought to material thinking. Handling revealed the limits of conceptual thinking. It took the work elsewhere" (p.33). Similarly, the clay and technology seemed to match each other in their demands.

---

[76] Dolomite is the primary component of sedimentary rock and is used in Ian Hacking's book *The Social Construction of What?* (1999) which Latour (2004) uses to dismantle Heidegger's dichotomy between objects and things.

Figure 20: Final versions of the sketches which begin to include details of making process, lists, textures et al.

Originally we had envisioned the whole object as clay with a thin porcelain layer that could be projected onto. However, due to the curve and the shrinkage of porcelain when firing this presented a large technical challenge. Both the digital and the physical components had their constraints and had been negotiated throughout the making process, considering other materials such as thick tracing paper to project onto or to project from within one mountain onto another. Other alternatives to projection such as an arduino-operated zoetrope that could be more flexible with size and could animate a specific sequence of words were discussed. It created a new series of more detailed sketches that we could use to consider the tricky amalgamation of technology and ceramics.

Figure 21: Raw clay (left) and fired clay (right) begin to embody the mountain ranges and Victors life through the illustrations.

126

Shared Curation

On the 9th July 2016 we had our first group meeting in the gallery at Stockwell Street. It was a chance for myself, Anne, Elwin, Sam and Freda to meet as a group and begin to visually situate the works within a gallery setting. The Stockwell Street gallery is a contemporary space with concrete floors, white walls and windows out to the street (designed by the architects as a way of visually inviting the public in). It was interesting to see the participants in this new space and begin to move the practice to the next stage. This also created a shift in Freda's design based on seeing the actual size and scale of the gallery and considering where the works would be placed.

Upon reflection, Freda said that the project has had different functions for her over the past year. At the beginning it felt very necessary to talk about Victor and make this artefact to honour him; now more and more the emphasis is shifting to a playful re-imagining. As her life moves on, she is re-identifying herself and situating herself further within the community in Berkhamstead. As the artefact develops its tangibility and moves from the emotional and conceptual to the technical ceramic construction, it parallels Freda's own process of reintegration. She now feels ready for it to be given over to the exhibition and become a tool for public curiosity and inquiry. These feelings also reflect the growth of the collaboration, which has empowered her to think about her husbands life story as a creative practice. She is curious about what people may think and how they will respond to this artefact. This expansion from process to public experience is explored in the following section and allows the collaborations to begin to form the curation.

V.
EVALUATION OF CO-DESIGN
METHODOLOGY AND INTERVIEWS

This section uses narrative as a methodology (interview transcripts App.5, p.212) to consider some of the underlying similarities and differences in the way that the participants and practitioners are framing and beginning to talk about this research. The interviews specifically focused on personal experiences and descriptions that have emerged from the process. This took the form of five short 10–15 minute filmed interviews. These interviews have also been used to create four short films that show the situated nature of this process, filmed within the participants' homes. The interview questions aimed to gather the reflections, stories, and emotions that have been built around **the process, artefacts** and **upcoming exhibition**. They used prompts to stimulate the conversation and delve into particular areas of interest but aimed to be non-intrusive. The film crew set up the equipment and then left in order to give the interviewee some privacy, but the camera and associated apparatus did impact the way that participants talked about the research, based on their own background[77].

The Nature of this Collaboration

I begin my discussion through collaboration and co-design. Co-design (Ch.4, p. 99) has been at the centre of this creative collaborative process. As my co-design process does not use specific tools or probes it is scaffolded through the paired collaboration. By having a creative practitioner work with someone who has been through bereavement the collaboration has grown. This growth is important, as at the beginning of the process the relationship may focus on how to form a creative inquiry, but over time this shifts to a collaboration in which critique, discussion and contextualisation form the works being produced (as a process this can be most clearly seen in: App.4 p. 203). The developing collaboration is used to create an inclusive process where roles become mixed-up and collective creativity is applied to the whole design process (Sanders and Stappers, 2008). The levelling of skill through building confidence and knowledge of the deceased

---

[77] Freda, who has been involved in politics for many years being the mayor of Berkhamsted and used to giving short statements, was unable to elaborate in the way that she normally does within the sessions. The camera seemed to freeze her slightly and the statements felt quite contained during the interview. However, when we were taking the extra footage of her making ceramics in the kitchen and looking through her sketches, she came alive again. Elwin on the other hand was very nervous during his interview. It felt difficult to see a man who I have always known to be very bubbly and confident getting so nervous in front of the camera. Within his interview he states "I'm never inhibited about putting my work out into the world itself. I'm inhibited about putting myself into the world but not my actual work" (Appendix 5, p.218, line 264–265) and this is quite telling. When Anne chips in he is able to calm down and chat to her more naturally about the process. This shows the closeness of their relationship and how they are both able to support each other.

through narrating has taken on different roles within the various collaborations. For Freda my knowledge of Victor was very important to the process:

> "I was very amazed at the beginning, how short it was a time before I felt that you who had never met Victor actually knew him as well as I did and I felt this was extremely valuable for me, it gave me a great deal of pleasure that, that was happening and I think it made it easier for the whole project to move on" (App.5, p.213, line 11-13)

This reflection is telling in a few different ways. It was not only pleasurable for Freda, that I took the time to get to know Victor, but it allowed our positions to become mixed up from very early on (Ch.4, p. 118). During the second session, talking about Victor and talking about making were interchangeable as we weighed one process against another, contrasting materials with contrasting stories. It also helped to construct a sense of ownership where Freda talked about the life that she has created now containing lots of **new and interesting things** and sites this project within that collective. Within all the interviews there were discussions about ownership and the way this was shared and negotiated throughout the process.

For Anne and Elwin there was the additional negotiation within their own collaboration, to me as the project facilitator. Anne refers to her concern at the beginning that "this is Stacey's project, its her PhD and its actually very important" (App.5, p.217, line 156–157). This froze her and it made her question whether she was doing the right thing by following the brief. As the project has progressed this anxiety lifted, "actually there wasn't a remit… the way you have managed it/ run it… has enabled it to be yes, your project but actually has enabled it to be my project too" (line 158–159). This has been fundamental to the way the collaboration has worked and the relationship that has formed between Anne and Elwin. You can feel the deep bond as they describe what it has meant for them to work together. Anne says "at the very beginning, I was very anxious about doing it. I thought I needed to be an artist of some sort and I needed to have technique" (App.5, p.215, line 86–87) but "it has been **fantastic** … [Elwin has] **held my hand** all the way through without being intrusive at all" (line 93–94, emphasis added). By sharing the materials Elwin introduced her to and developing proficiency, she is able to take more control thinking about the effects she is trying to create.

Elwin echoes how this journey from anxiety to proficiency in materials has changed their relationship. He talks about how he took Anne through a "fine art

through process… art school [approach]… that very same process" (App.5, p.218, line 189–190) that he knows so well from his own work as an artist. He observes Anne as he could never observe himself going through the process and provides the scaffolds intuitively when he thinks she needs them. He states that he "didn't want her to feel that [aloneness] because when you do fine art you don't have that [collaborator], you sort of are just thrown in there so and people will try and help you but they don't want to intrude on you finding yourself" (App.5, p.218, line 202–204) and it is this belief that makes him draw strict boundaries around his participation. He wants to intervene just enough for her to gain momentum, and this is evident in the expanding portfolio of works that is spilling all over the household. Elwin has to get to know Anne's language and uses the materials as a mode of doing this because when you are "creating a language its like a dance" (App.5, p.219, line 225). Ingold (2013) refers to the 'dance of animacy' (p. 101) as he talks about how the person, air and kite do not interact but 'correspond´ to each other. Anne needs Elwin to correspond to her, to alleviate her anxieties and they both need the materials to mediate this collaboration and share a common language.

As the material language evolved so did their collaboration. It shifted from Anne asking **how to do things** to discussing the details of the work itself. Elwin has talked about how he is "bowled over with the process she has gone through and how she's handled everything" (App.5, p.219, line 228). He has found this particularly poignant to watch, as during his own bereavement for his mother he **stopped painting**. Elwin still uses his painting skills but claims he has changed materials, from paint to people: "I no longer work with objects I work with subjects. People are subjects that matter" (App.5, p.221, line 302). In the same way that talking about my grandma's thimbles (Ch.2, p. 47) transformed them from objects into 'matters of concern' (Latour, 2004) that I want to care for, Elwin has paid such careful attention to the flow of Anne's work that touches on this dilemma. In fact he is still working through paint, despite the fact that in their sessions Elwin does not work on the paintings; he mediates them, he analyses them, he critiques them. In a range of small intricate ways this forms the way the works evolve. This collaboration is moving to a **professional** level. He gives Anne status by admiring her progress and really **appreciating** the beauty of her work; Elwin says its "exactly the same as I would work with my friends … because in many ways they're doing the same thing you're trying to do. They're trying to come to terms with something" (App.5, p.221, line 311–313). Elwin is bringing Anne to the point where the exhibition will be the pinnacle of her progress as "its really important because you shared these with me and I think

they're so beautiful and so poetic… I feel it would be a crime for you to sort of hide them away" (App.5, p.220, line 261–262).

My collaboration with Sam has felt similar in terms of the professional critique and my role in building her confidence to show this **unpackaged** work. As an art therapist much of her practice remains linked to her experiences of art education. She describes how the collaboration has given her the **structure** and **grounding** to push forward with her practice but at the same time she has "never felt like its not [hers] and actually it does feel quite mutual" (App.5, p.222, line 346–347). She describes this as a **friendly perspective** that pulls you out when it is getting too **consuming**. Telier (2011) calls this perspective 'cultivating the art of seeing'. Although Telier is talking about an individual design process, co-design can use these processes as a reflective scaffolding "working with metaphors, analogies, and themes … [to] help express, contrast and intensify the design concept … to evoke imaginations rather than prescribe" (Telier, 2011: 21). Sam considers the collaborative experience as lasting beyond the sessions and explains how she is able to keep an aspect of me with her as a reflective voice throughout the process.

Overall the participants' experiences of the research as documented in Appendix 5 are captured in the words they use to describe what this process has meant to them. They have considered it **valuable** (line 13), **helpful** (line 70, 180, 409), **interesting** (line 71, 126, 144, 164, 333, 370, 466), **different** (line 84), **exposing** (90, 132, 453), **challenging** (89, 92), **therapeutic** (line 112, 419), **fantastic** (line 162), **emotional** (line 256), **wonderful** (line 295), **fascinating** (line 331), **grounding** (line 344), **powerful** (line 459) **rewarding** (line 462) and **unique** (line 470). This speaks to the nature of the co-design process and the collaborations themselves. Even though the experience was exposing and emotional it was also fantastic, rewarding and helpful. This challenges some of the ethical procedure around those we label as vulnerable. Artistic methods can be conducted to explore how people's vulnerabilities can allow them to probe into the boundaries of their own experiences without feeling used as part of a research process (this reflects the ethical grounding of exhibiting research discussed in Ch.3, p.82).

Meaning and Making

Meaning is always a challenging thing to ask about within an interview. Meaning is often difficult to place or intellectualise. It gets mixed with feelings and needs deep reflection. It was easier to talk about the meaning of the process and the

themes within the artefact, rather than the artefact itself, which was a struggle to articulate. This was made more challenging as participants were reflecting on it personally but also flipping it to consider its meaning in a public setting. Depending on their own approach to making and exhibiting different aspects of meaning gained importance and were reflected on.

Freda spent much of the interview discussing the meaning of trains in Victor's life. This included a wide range of stories including: potential **train accidents**; Victor's interest in the **economics of trains** and how they took part in the economy; Victor as a boy observing the **limited amount of rolling stock** and bombed railway lines during the 2nd World War; Victor being an **engine number collector** who used to go all over London in this pursuit; the man who helped during Victor's illness because he was **another trainman**. Through this we can see how the train gains body and detail, it is not a 'thin symbol', as De Waal would say (Ch.4, p.108). By editing Victor's life through trains she is both embodying and exploring the **trainman** and her own fascination and love of him that grew into a shared passion. She affirms her own entanglement with the trains into two statements:

> "I have nothing to do with any of this [history, but] if you live with somebody that long and there is something that's important to them, I can almost believe I was there and in that sense it means a lot to me, yes" (App.5, p.214, line 44–46)

> "Most of the family couldn't understand why he was so mad as to be interested in trains, its very lucky that he married a wife who was more than happy to go and join him and find out… its something that we really did enjoy doing together" (line 49–51)

By considering the function of the trains within their relationship and bringing them into the artefact she is able to share that story, and those *clay stories* reaffirm Victor's presence. This reflects Miller's (2010) statement that 'stuff creates people' (Ch.2, p.47) but by turning this stuff outward it also allows the dead to engage with the world through their things and the bereaved to position themselves as makers who have a deep understanding of the complexity of these artefacts. By reframing it as an artefact for exhibiting she shows her interest in sharing that story saying that she "will be very intrigued to know how [people] will react" (App.5, p.214, line 61) particularly if they will be able to see Victor through the trains and if they "will actually pick up on the story" (line 64). Freda, in contrast to the other two participants has designed the artefact specifically to

be read, through the use of projected words and the structure of the three mountains, which encapsulate different periods in Victor's life. She has given the piece a **right order** which can be read both visually and materially but which is different to either Anne's view of her pieces moving from **dark** to **light** and **static** to **fluid** as traveling "with the art work through some of those dark things" (App.5, p.216, line 123) or Sam's desire to be comfortable with exhibiting in the gallery space by saying "its ok for it to just be a strange object… [with] this strange stream of bibble that's going to be kind of meaningless and weird." (App.5, p.222-223, line 341-363)

Sam, as someone with an arts education background, struggles the most with the nature of the exhibition as she feels that what she creates should be **palatable within that environment** creating a personal tension between a **fitting** *process* of making and her own understanding of art, craft, making and exhibiting. Although Anne is very anxious and considers the exhibition **quite exposing** she is also quite solid in her view that the exhibition itself doesn't really change anything about her work and that it is helping her to view herself and the work in new ways. At the beginning of the interview she affirmed her view of Tim, her deceased husband, as the **creative one**. As a musician and photographer his creativity was always in the focus. Therefore the artefacts that are being produced as a collection of textures are as much about her own emergence and re-identification of herself through Tim. She describes how she is thinking about herself **differently**. Unlike Freda and Victor's **trains**, which were a shared passion during life, Tim had ownership of the **creativity** identity in their relationship. Therefore, when Anne reflects on her paintings saying "I look at these and I think, sometimes I think actually they're really quite good some of them and that's a really unusual experience" (App.5, p.220, line 274–275), she is beginning to **surprise people** by taking on some of the qualities associated with her late husband and **surprising herself** by finding that she is its equal.

This is maybe why she has been unable, so far, to integrate her husband's music into the pieces. Her proficiency in the materials is reflected in her changing relationship to the pieces. As the pieces become **more fluid** she states that if "I feel like I want to have music over it or if I could do musical notation I would be doing that. If I had beautiful handwriting I would be writing" (App.5, p.216, line 129–130). In making, and in design in general, it is always challenging to introduce new materials. A piece can easily become overworked and lose the essence, and her husband's music is a very particular kind of material that will change the way she views the pieces. Its introduction brings up questions of

ownership: "It was all about Tim, whereas now it's all about me… Tim and Elwin and this process have allowed me to discover something of myself" (App.5, p.220, line 269–273). Nevertheless, her reflection on the role of music is clear in the pieces themselves. They hold a kind of *musicality* that Anne identifies with. She has in a sense translated the music with the pieces themselves. Elwin likens the collection to Abstract Expressionism and affirms the value of the collection. The *movement* within the pieces that Anne refers to and the thickness or thinness of the textures function as textual crescendos and diminuendos within the collection, which reflect how her own emotions grow and soften over time. The limited colour palette of black and white emphasises the textures and focuses the eye upon the contrasts.

For Sam the meaning is predominantly situated within the making process, where she grapples with the meaning of Charley's life. Charley is a school friend who she "loved to pieces for a very short period of time" (App.5, p.222, line 317) and who died prematurely. She describes the *visceral human moments* and how this process has created a way to "put these things together and to actually come up with something tangible" (App.5, p.222, line 330–331) that slips fluidly between feeling and thinking. Sam is experiencing Ingold's (2013) 'thinking through making' and 'making through thinking' (discussed in Ch.4, p. 108) but in addition she is 'feeling through making', 'making through feeling', 'thinking about feeling through making' and 'making through thinking about feeling'. As a participant who professionally has been *flipped* from being an art therapist to exploring her own loss through making, she experiences the process through a great deal of reflection both personally and professionally. Although in one answer she describes the piece as a *symbol*, through the mushroom, it is due to her desire to distinguish her own *private intimate moments* from other people's *viewership*. By transforming it into a symbol she is able keep that which is most intimate while still opening it up for public engagement.

The combination of the concept of the mushroom confirms in a similar way to Freda the role of the mushroom within their relationship: the mushroom birthday cake, Charley pointing out mushrooms when they were sneaking off smoking and the photograph with a mushroom on her shoulder. The mushroom also affirms her understanding of the current relationship she has with Charley, who she has now known longer in death than in life. She describes how her experience of Charley today mirrors mushrooms, in the sense that "things pop up" (App.5, p.223, line 385) unexpectedly and fill her brain like rhizomes. This understanding of how mushrooms spoke as much about Charley's life as her death gave rise to

the choice of materials. Sam had been grappling with ceramics or painting as those are the materials she is used to but it didn't ***quite resonate***. The materials mattered. How the mushrooms were made mattered. As the process moved on her thoughts on repetition led her to dry felting. The way that hundreds of tiny incisions made the soft and fluid fabric solidify into mushroom form embedded Charley and was rewarding as it contained "some of the meaning in it" (App.5, p.223, line 390–391).

Her rich description of how they are made emphasises this further because "you sort of make them up here [indicating chest] they sort of become nurtured" (App.5, p.225, line 443–444). I think of Sam nurturing her collection of mushrooms into the world and Elwin's description of Anne's work that "you can feel when you go really close up, her thumbs being ruined by the textures … like she's been digging in the earth" (App.5, p.219, line 232–233). Both Sam and Anne experience the making through their active engagement with materials; the materials produce different experiences that **animate** them. Anne tells the story through her material descriptions, how "it started very dark and… quite slashy" (App.5, p.215, line 80–81). This entanglement of Anne with her making talks about the differences between a "piece of inert matter that you *act upon*… [and] something active with which you engage and interact" (Malafouris, 2013: 150). This interaction is on the micro level of skin follicles with particles of paint and on the macro level of a collection of works. She talks about how being close to the work, the ***physical process*** which has actually taken the skin off her fingers, has allowed her to be in ***touch with feelings*** in a way that goes beyond thinking and talking. As Sam and Anne are working with new materials they create meaning through the process of making. This work illuminates and speaks to McCoulough's (1998) approach to thinking in *Abstracting Craft*. An intuitive process of negotiating – how something should be formed through 'tools, medium, skills and intent' (Ch.4, p.107) – is explored and can be enhanced by Ingold's (2013) notion of making as a process of 'correspondence' between the material and the maker (p.31).

Aesthetics through Process

In this research, questions of aesthetics become entwined with feelings and process. Two out of three of the participants chose to use a material or making process that was unfamiliar to them. This meant that part of the process was learning how to achieve the desired communication within their chosen medium. The learning process lent itself to working with iterable craft processes that could

be reproduced fairly quickly in order to move closer in each stage to the desired effect of the work. This labour and reproduction created confidence. An affinity is created between the participant and the craft form. Even in the case where the participant has been a ceramist for many years, technical issues and the ambition of the project required skills yet to be mastered and helped to drive forward the practice (Ch.4, p.124), identifying the design with more clarity.

Sam in particular labours over the fact that she does not want the process to be packaged and that this pushes her to new aesthetics that come with the process. She is left with a problem. The felted mushrooms, however appropriate, do not speak to her own aesthetic taste. She describes the first one she ever made as a **pink gaudy cheesy little thing** but peppers this with laughter. She knows it is a good encapsulation of their teenage relationship but feels slightly embarrassed by its presence. It feels fitting. Not to the gallery space but to their relationship. In her struggle Sam reveals the vulnerability of someone with aesthetic training that leaves them open to be judged, and I empathise with this. You can see the physical conflict and her desire to hold onto a position of naivety when she grapples for labels and finds **Outsider Art**. Sam is using Outsider Art to situate what she is doing outside the art world so it is not defined by those aesthetic principles. In contrast, Elwin is interested in a different approach to aesthetics where "beauty [is] coming out of something using raw materials" (App.5, p.218, line 184–185). This is of course different as it is not his work that is being displayed but it is this material focus and commitment to authenticity that he pursues with Anne, which soothes some of her predetermination about what should be placed in a gallery. Elwin additionally does site works and artistic movements, comparing Anne's work to abstract impressionism.

Moon (2016) on the other hand pertains to questions of aesthetics, which are not located in art produced but on the limitations of the art world (referred to in Ch.4, p.103). She claims that through exhibition, art therapy can be used as a way of opening up aesthetics to challenge the inclusivity and hierarchies of art. Rubin (2016) also claims that the aesthetic tastes of the art therapist can cloud their perception of clients' work, "I believe that few art therapists judge their clients but many judge their artwork. For me, art and artmaker are fused; therefore, I cannot be wise about one and not the other" (p.5). It is this relation of person and process along with questions of hierarchy that I intend to also challenge head on in the curation of the exhibition. This will be approached as a co-curation; but as Mahony (2001) comments not all projects that claim 'multiple authorship' do so and it is in the details that hierarchies are felt. She explores this through the

Christine and Irene Hohenbüchler exhibition, *We all peel the onions* and the subsequent publication *Victorya* including some responses from participants. This exhibition reveals a range of ethical issues about what it means to exhibit as a participant in community engagement, artistic or research collaboration: from the typography in the catalogue (small or tall letters); to the labelling of the sisters as artists and clients from the day hospital as group participants; to the curation where Mahony comments on how works are cut out with scissors and mounted as collections on fences so they appear as a mass rather then being appreciated as individual pieces. All these things together speak about what the Hohenbüchler sisters hoped to achieve out of their exhibition rather then deeply engaging in what it means to work with people. Mahony reflects "it was not to do with lack of mounts, or frames, but the lack of consideration given to aesthetic qualities and nature of the content" (p.58–59) and it was this combination of factors and lack of care that made people feel 'used' within this project. These works visually said 'therapy' and were about exposing hidden art but actually exposed people and put them on display. I have been very careful throughout this process about the introduction of these works into the gallery space without diminishing the vulnerability of exhibiting. The co-curation will ask questions about details such as labelling, typography, imagery, graphics, text, titling, mounting, framing, lighting, access to gallery and many more. As a researcher and designer I am interested in how we can expose the making process to enrich the aesthetics we have created and give body to these encounters with bereavement, materials and things, but I will continue to ***follow*** the research (App.5, p.226, line 488) guided by the collaboration.

One question is how to tell the story of the research and these three collaborations in the same space? Labelling or even knowing how to encapsulate the process into singular words has been challenging. There is a lot of baggage that comes with discipline-focused words and I am grappling with moving beyond them. I want to speak about what the artefacts are actually doing. Words like ***embodying***, ***containing*** and ***animating***, which are drawn from my design lenses (Ch.2, p.69), help me to do this. Sam intuitively responds to this saying:

> "Labels like art and craft feel quite static and imbued whereas the words
> you chose … they're also more process, movement, fluid-based words
> that … encapsulate something not being static and actually having room
> for it to be more" (App.5, p.228, line 564–566)

The 'more' that Sam is referring to I believe is aesthetics. Labelling is necessary once you place these things in the public realm. They need to be talked about or they will fall into the gallery association of art and be folded into this limited viewing. As Hillier described (1994; Ch.2, p.56) by placing her art in a vitrine in the Freud Museum, her work was viewed with the detail of a museum gaze. People scanned across the rows and visually read the boxes. The way these artefacts are curated will affect people's perception and needs to be highly nuanced if they are to reflect the nature of the processes.

I have paid particular attention to the words used within these interviews as descriptors for the artefacts and processes. Most of these have not come from the prompt 'labels' but rather by gathering them from within the description of the five interviews. Words like *story* (line 47, 64, 119, 353, 356, 463, 579), *backdrop* (line 107), *dark things* (line 123), *movement* (line 128, 565), *fluid* (line 129, 230, 565, 582, 609), *surprising* (line 153, 226, 325, 495), *physical* (line 178), *authentic* (line 204), *natural* (line 208, 210, 219, 433), *organic* (line 104, 234, 493), *emotional* (line 256), *visceral* (line 326, 342), *pure* (line 342, 439), *grounding* (line 344), *capsule* (line 355, 544), *snippets* (line 356), *contained* (line 339, 357, 390, 579), *condensed* (line 358), *dynamic* (line 362), *therapeutic* (line 112, 419), *expanding* (line 452), *exposing* (line 132, 453), *powerful* (line 459), *sharing* (line 463) and *celebratory* (line 477) begin to give characteristics to the artefacts, processes and people.

When thinking about the role of words in relation to aesthetics and moving beyond disciplinary boundaries, I refer to Gunaratnam's 2007 article (previously discussed in Ch.4, p.108) *Where is the Love? Art, Aesthetics and Research*. Through its exploration of a situated, unfolding of artistic practices it shows the tension in an intellectual approach to writing about creative processes. Gunaratnam describes how arts research or research represented in artistic forms can surprise you by demanding intervention and representation of things found. Lange-Berndt (2015) collects a series of artistic essays that show how following the material provides a different gaze to aesthetic quality, expressiveness or symbolism, which are typically used in artistic analysis. Opening up to the meaning of materials used in artistic practice allows them to transcend their art boundaries and engage in conversations of the everyday (p.16).

McGuinness (2016) supports this position claiming that "being an artist is not simply about being a producer of work in isolation. Rather it is about being deeply embedded in society and importantly, having shared responsibility within that

society… By doing so [he engages] with 'life' operating alongside theory" (p. 158). Miller (2010) also uses descriptions of the everyday in a similarly material way. He grounds his research by telling the stories of his journeys and people he has encountered. He enjoys this "immersion in the lather of ethnography, luxuriating in the detail" (p.41) and through this is able to convey a vivid visual of how Indian women come to be understood through their saris. Therefore the labels begin to develop a vocabulary that is appropriate and empathetic to the lived experiences. They enrich the 'design lenses' (Ch.2, p.69) with the experiences of my participants, which in turn guide the aesthetic development of the exhibition. Through these frank accounts I come to understand the artefacts and the people that make this research.

Digital Stories and Co-Crafted Legacy

Although the artefacts have been designed with digital content in mind they need to be physically made before we can test their properties as hybrid things. Discussions about how to embed the projector in Freda's ceramics and the speakers in Sam's mushroom installation have informed and pushed against the process of making. The participants have alluded to how these developments might work and how they are expanding their thinking. Freda talks about how she has begun to understand the concept of digital heritage through her story of "Uncle Fred made a stool" (App.5, p.213, line 5). She succinctly explains her understanding of digital heritage and reflects on how it changes her concept of legacy. She describes the process as "converting that [stuff]… into something comfy that you can actually look at and say this explains what Victor was about". It conveys some of her feelings about the way that Victor's office has been encapsulated within the artefact.

She also uses humour to consider how the introduction of the digital into Victor's legacy extends him into her present, which is becoming increasing digital, as she becomes active via e-mail and Facebook. She claims that "in one sense it is distinctly ironical to have a digital heritage for Victor and to transfer the things that he was interested in and the things that he has done into that sort of form" (App.5, p.213, line 22-23). She identifies the translation of Victor as giving her an interesting new vantage point from which to see him. I believe she means that through translation she is able to see many aspects of her husband's life at the same time and this helps her to place the artefact as a kind of digital heritage that expands his presence in her life. In parallel to this, Anne has a collection of digital music that is very precious to her. The music was produced by her

husband but so far throughout the process she has been unable to access it due to the visceral emotions it would produce. Still her pieces are themselves textually musical, as she has translated the music into them. She encapsulates her emotional journey to access the archive in two statements:

> "When I started this all originally my idea about it was to think about him and what he meant to me and there's all these words and music so I have been struggling a lot trying to incorporate words into this, hasn't really worked very well." (App.5, p.215, line 76-77)

> However as time has progressed "I feel like I want to have music over it or if I could do musical notation I would be doing that. If I had beautiful handwriting I would be writing." (App.5, p.216, line 129-130)

Anne has struggled with this process of adding digital layers of content to the work, as she is not confident within the digital medium. In addition to this the music is painful for her to access and she worries about her family's reaction to it. She talks about the ***profound*** experience of having a reading from the poems of Prudentius[78] at the graveside. The references to ***earth*** and ***nature*** fit to the work she has produced and she considers how this poem could be integrated into them. This integration is something we will continue to tackle as we move towards the final exhibition.

Sam also has an archive of sound. It stems from a Dictaphone that her friend Charly used as a way of leaving messages for her. We are using these voice clips directly in the piece but merge them with other sounds that remind Sam of Charly, like a washing machine and a local truck that has her name on it. The spatial qualities of the sounds are important to her as the mushrooms are rhizomatic. The distribution of the sounds across a range of speakers with a pre-designated hierarchy will allow the more private sounds from the Dictaphone to be softer and the other everyday sounds more domineering. By structuring it in this way it is not a literal retelling of stories or even translation but a kind of sonic bricolage that animates Sam in a way that will not be experienced by other viewers. These are ***little symbolic stories*** from another time. For Sam, the Dictaphone is a significant object from the archive as "its literally this little time capsule from back then so they are very direct little moments in time, little stories, snippets… contained in the piece" (App.5, p.223, line 353-357) and by

---

[78] Aurelius Clemens Prudentius was a 4th century poet who wrote, "Take him, earth, for cherishing." This poem is a popular reading for funerals and focuses on the body passing into nature as it decays and the spirit finding its way to God.

augmenting this with extra sounds she is creating an environment for Charley to be embodied in partial glimpses for deep listeners.

Exhibitions

Although the exhibition is yet to be fully realised it has a very clear function as an ending for the design process I have described throughout this text. This was something I was interested in thinking about within the interviews and it is ethically important to help participants process the fact that the collaboration is coming to an end. Freda likens the idea of an ending to bereavement itself and how people feel **deprived** when there is no clear end. The exhibition gives this clarity to her and additionally allows for feedback that further extends the learning beyond this research. Anne similarly talks about a **very defined period of work**, that the project fits "in between the date we started and the exhibition which is the actual ending" (App.5, p.217, line 142–143). For her this creates a conceptual **container** for her body of work and links it strongly to her period of bereavement. She claims she is not ready for the end yet admitting that she has not yet **got to grips** with it but is interested to see her work "in relation to other peoples" (App.5, p.217, line 140). Elwin engages Anne with the ending and begins to prepare her for it by saying that he is "very sad about the ending but … also so elated to see, watch what Anne's created" be exhibited (App.5, p.221, line 293-294). They share a moment in this thought and reflect on their process; ethically this is important, as the boundaries of their relationship within this research are clear and there is structure to their collaboration.

Sam describes the ending as a **very definite anchor**; she sees the power in this structuring of the process. She also needed the length of the process to come to terms with her aesthetic anxiety about the exhibition. When talking of endings, she states "endings can be good, they can be bad [laughter] but I think it's a way of drawing a line under something in a very positive way and it has the potential to be really really rewarding" (App.5, p.225, line 460-462). She refers to a coming together and creating of a space for sharing the works and stories of everyone involved in this collaboration. The sharing during the co-curation is another scaffold before the work goes public; it transforms it from **my** work to an exhibition, which is by nature plural. Sam also sees this as a way of "honoring that person in a way that [she] had never been able to before" (App.5, p.225, line 465-466), which is particularly poignant as she was unable to go to Charley's funeral. For Sam, this is an opportunity to have really delved into this relationship, to really have understood it in a **unique way**.

The Afterlife of Things

"I am not sure I can cope with the afterlife of what I have made"

(De Waal, 2011: 16)

Will the things we have made live on after the exhibition? Is it important that they do? By creating these pieces for an exhibition the participants have given them a function and constructed them as installations and experiences. It is difficult to say how these experiences would be re-created or used within a home environment or whether they need to be. Freda states that the ceramic structures *will exist* after the exhibition and she is quite comfortable with the idea of it joining her collection of ceramics in the garden and eventually succumbing to material decay "when the rain gets on it and the frost gets in" (App.5, p.215, line 67). It shows how comfortable she is with the piece. She is happy to have it around but does not need to find a **use** for it. It will become part of the 'creative density' (Telier, 2011: 34) of Freda's home, which inspires her as a ceramicist in her making. I asked Sam this question, off the record, when we were filming her piece in the forest. As we both looked over at the felt mushrooms on their moss base, sitting unassumingly on a grassy knoll, she decided in that moment that after the exhibition she would like to leave them around the forest that so reminds her of Charley. She likes the idea that people will come across them and smile wondering why they are there, and it is undeniable that they seem to fit to this environment, even the colours seem less garish as we stumble across a florescent orange fungus creeping up a log. So they will continue to function in some way, moving from the gallery to guerilla art within the forest. But she will keep one. One mushroom as a memory of the process.

Critical Evaluation

This section has drawn from the interviews a range of views and experiences that give insights into the collaboration, people's ownership of the works, the process of making, construction of meaning, our relationship to aesthetics and how the work becomes re-framed through exhibiting. It responds to the research question «how can collections of things (objects and data) be used as material to embody the relationship between the living and the dead» but flips it slightly to «how embodiments of materials collect things, constructing new relationships between the living and the dead». This focus on materiality has informed approaches to making that capture not only the relationship between the living and the dead but also how the dead form us and prompt a particular telling within this

collaboration. In reference again to De Waal (2011) and Gunaratnam (2007) the mode of telling is important – these stories aim to enrich their subjects in a range of different materials and media. Despite this, they do not all approach the relationship between materials and things in the same way. It varies throughout the process and between participants: Freda being the most focused on how things are translated through materials (Ch.4, p.116) and Anne being the most embedded in extracting meaning from the materials and making. The detailed way that the participants are responding to, 'corresponding' with (Ingold, 2013) and 'thinking' through (Lange-Berndt, 2015) materials shows how materials become interwoven and develop people's stories, memories and feelings. These experiences are highly varied but share a sense of embodiment where the focus shifts between the deceased and the living.

Collaboration and Narrative

The nature of collaboration and its role in the ethical narration of the research has been explored through a comparison of the ethical framework and approval structures discussed in Chapter 3 (p.71), in relation to the description of how the collaboration actually functioned in Chapter 5 (p.128). By working with rather than being protected from their vulnerability, the participants were able to negotiate different approaches to translating and finding a place for the dead. They were also able to reframe their role within the research and through this claim ownership of the process. The sharing of ownership through flexibility, respect and the development of a shared language is fundamental in moving from participation to collaboration. Questions of how a collaboration is formed, sustained and planned for have run throughout the text creates a further research question: «How does a top to tail approach to co-design help to frame design research within sensitive contexts?» This has been particularly relevant due to the wider application of co-design within health, social or business contexts (Ch.4, p.99). There is little conciseness of how co-design, as collaboration, can be applied to a range of interdisciplinary settings e.g. how co-design is adapted to experience-based design within the NHS (Bowen et al, 2013). When working in sensitive contexts it could be argued that, if co-design is only introduced at particular stages of the design process, it may begin collaboratively but as solutions or products begin to form they impose certain design decisions on this community. In the design industry, slippage between terms like engagement, collaboration and experience shifts the ethical pre-conditions of what it means to create patent-centred, user-centred or collaborative approaches. By defining co-design as a top to tail approach, it states

clearly that the collaboration must be negotiated throughout the entire process if it is to be truly collaborative and inspire participants to develop their own confidence in their design, artistic, craft and making skills. The collaboration between Elwin and Anne has been particularly important to this question as it shows how the process works when I am not directly involved and alludes to the scalability and reproducibility of it[79]. Anne's growth in confidence has been a testament to the research methodologies pursued and shows how design and artistic methods can create their own ethical conditions that work in different ways to the current ethical protocol within sensitive contexts, such as bereavement.

This discussion around ethics has been distinctive and challenging. Ethics can be seen as a creative constraint as it both halts and fuels the research process. I have considered ethics as a creative restraint, which has informed particular parameters in the development of my practice research. One example was the discussions around data and anonymity within the ethical approval forms in Chapter 3, which led me to consider more deeply the role of transparency within my research (p.80). In this research the main ethical conditions were to promote transparency of the process and collaboration through flexibility. However, the ethical structures in place also help to challenge researchers in developing their own perception of ethical practice. The speed of the process of ethical assessment creates thinking space. These questions of ethics are predominantly addressed in Chapter 3 in which doing ethical procedures forces a form of reflective practice, making the researcher question the impact of their research prior to beginning it. This reflective practice, when done in a deeper way through consultation and clinical supervision, can enhance the research and provide the designer with a deeper understanding of the contexts they are acting upon and the way that doing design in sensitive contexts should provide designers knowledge of where and how to intervene within these systems.

The digital age also provides new challenges for ethics in terms of confidentiality and time-based deletion. As social media promotes a society of sharing and documenting even our most intimate moments – along with research guidelines and governments moving towards agendas of impact and public engagement – questions about the nature of practice research in relation to ethics need to be

---

[79] As the co-design methodology is individualised and flexible, it is important to note that the sessions between Anne and Elwin seemed to have followed a similar process, the main distinction being that Anne and Elwin have seen each other on a more regular basis then I have with either Freda or Sam. This may be attributed to a few reasons but seems to predominantly stem from the fact that Anne needed to go much deeper in order to process her grief and explore her own creativity than the other two participants, therefore iteration and the development of a portfolio of works have formed the basis of their partnership. See Appendix 4, p.201 for a full description of this.

reconsidered. When working with vulnerable groups, questions of transparency and choice, where control of data is shared, may come to supersede automatic confidentiality and deletion.

Impact on Design

In collective curation there are shared questions of what the works mean when they enter the world and how they correlate with each other. How will the public engage with the exhibition and come to understand the artefacts that they experience? This is more challenging, as the artefacts do not fall into neat disciplinary categories, or even functional categories like memorial or tribute. The framing of these pieces within the gallery will push the public towards artistic interpretation. This brings me back to Hillier's playful approach to allowing her art works to engage with Freud's things in the Freud Museum, where both collections are able to contextually grow the other. We have a similar tension at place here between the framing of the dead as artefacts, but also as three distinct people: Victor, Tim and Charley, and the public's experience of them through the institution of the gallery. Unlike Derrida's archives these artefacts do not desire to 'return to origin' or be folded into memory (Ch.2, p.56). Instead they use personal archives as a way of **embodying** and translating a person conceptually. This is closer to Steadman's understanding of the historian breathing life into the archives (Ch.2, p.60), or De Waal's use of the archives to talk about history through things (Ch.2, p.65). This research has focused on the creation of artefacts as a way of producing knowledge about the relationship between bereavement, crafting and digitality. This is achieved through exhibition. There is a level of collaboration and trust that needs to be developed in order to explore the stories we want to tell through the curation – a negotiation of space, aesthetics and experience. In addition to this, emotional exposure and a fear of being judged need to be managed within the collaborations, particularly in relation to differences in skill level and experience in making. This is something that has emerged from the collaborations and impacts the way co-design may be explored as public engagement through co-curation. As with speculative design, the exhibiting of co-design may create new forms of discursive knowledge and show how the process of collaboration may be applied to a range of settings and empower people to move beyond current hierarchies e.g. client or patient. It also pushes against the preconception of what exhibiting a piece means e.g. what does it mean to exhibit a design process rather than a product, fiction or speculative scenario? And does doing so contest particular categories or aesthetics of exhibiting? As part of navigating the co-design, my role in this

process will be to use the labels that were produced from the interviews (Ch.5, p.135) and to instigate a range of group meetings that will filter down to a detailed consideration of aesthetic and thematic principles embedded within this curation.

Barrett and Bolt (2014) claim that the move to situate studio enquiry within the wider cultural arena demonstrates the way that these curatorial practices produce knowledge that may be applied to multiple contexts and can further support interdisciplinary exchange. For example, the exhibition can form an educational role. The gallery is situated within a university that deals with bereavement within the student and the staff body. The exhibition is both an output and an integrated part of the process, one that signifies a sense of completion and achievement for the participants (Ch.5, p.141). Making the work public gives it an additional layer of meaning and connects the three works within one space, which situates the process as a unifying factor. This is supported by Carter's (2004) proposition that exhibiting creates a new form of universal logic from the individualised process of studio practice. It also responds to the Keaney et al's (2007) *Art Council England* report concerning the value of the arts that can be summarised in three main, interconnected themes the arts provide a "capacity for life, building an individual's understanding of the world and their place in it; the arts enrich the experience of life, bringing colour, beauty and enjoyment; and the arts can have valuable applications in other contexts, particularly social and community settings." By closing the design cycle with an exhibition of works produced through the research, I am not only deeply valuing the contribution and journey that the participants have been on but by sharing these life affirming experiences we can promote a wider social understanding of death and bereavement in the digital age.

VI.
CONCLUSION

Following on from the critical evaluation of the interviews, this section shows the impact of these critical reflections for particular communities and the research that can enable future work. This thesis has charted the contribution to knowledge made as a situated discussion and narration of the experience of collaboration, co-curation and shared creativity. It has drawn digital things into a material investigation (Ch.5, p.116) that has extended current research into digital death. It has expanded this through engaging the different constituencies of the hospice and art therapy to explore how digitality shifts their understanding of ethics and practice around bereavement (Ch.3, p.71). It has also created an approach to legacy that focuses on curation by drawing digital and physical things into dialogue with craft and making (Ch.5, p.107). This contributes to existing research that considers how 'material' (Miller, 2005; Miller, 2008; Miller, 2010), 'making' (Ingold, 2013; Moon, 2010) and 'networked approaches' (Latour, 2004; Latour, 2005; Latour, 2008) to 'thinking through things' (Telier, 2011) may refocus the role of the social in society and enhance the complexity of our relationships after death.

It has used narrative as a way of deepening our experience of legacy through the creation of the design lenses (Ch.2, p.69). They refocus from current trends of saving everything online (Ch.1, p.34) to the use of collaboration through co-design, editing our collections down to the meaningful aspects. This has created a mode of understanding how the context, site and materiality of legacy reaffirm its role in our lives. These inherited collections are creatively translated to extend the agency of the dead (Ch.4, p.116) by further integrating them into contemporary society. Narratives have also played a key role in positioning the participant and practitioner as equals within the collaboration. This stems from 'Narrating the Archive' where the practitioner engages in deep listening (Ch.4, p.117) to construct an understanding of the deceased through their stories, collections of things and the development of a crafted artefact. In addition to this, it showed how artifacts can be crafted to address questions of how to manage legacy in the future by complicating what it means to experience a person through their things.

Design and artistic methods have created different modes of translating bereavement, which have provided new lenses to understand our own and other's experience of it (Ch.5, p.131). The exploration of things and artefacts within this

research has extended these narratives to the public through exhibiting. It considers the function of co-curation as a way of extending the relationship between bereavement and making. It also integrates the design process and product, allowing for new forms of collaboration with participants or users (Ch.5, p.128), creating a defined boundary for the co-design process that exists between recruitment and exhibition. These collaborations add to the discourse of 'continuing bonds theory' (Walter, 1996; Walter, 2009; Walter, 2012; Walter, 2015; Neimeyer, 2001; Neimeyer, 2006) when combined with 'situated methods' (Simonsen et al, 2014), 'live methods' (Back and Puwar, 2013) and 'co-design' (Sanders and Stappers, 2008; Lee, 2008; Goodyear-smith et al, 2015). Together they question the role of legacy in our lives and how crafted artefacts that combine digital and physical properties may encapsulate our inherited collections, allowing them to be experienced in new ways.

Contribution and Impact

Hospice

This research gives hospices an insight into the full process and experience of participating in co-design projects and will impact the relationship between rigour and practice within research collaborations (Goodyear-smith et al, 2015). Through the interwoven research stories (Gunaratnam and Oliviere, 2009) and live methods it also shows how practice research can provide new ways of engaging specific communities in a top to tail collaborative design process. This provides new modes of understanding bereavement by tapping into the creativity of continuing bonds (Walter, 2012), particularly in relation to understanding the role of the digital within contemporary bereavement. Hospices can also use this research to consider the tension between practical, legal, ethical and care structures. Additionally, it provides more agile formats where ethical practice can be developed in order to further integrate digital and public engagement – through the development of research governance that supports transparency, personal choice and collaboration. Exhibiting can also be used as a collaboration that moves from confidentiality to sharing, allowing artistic methods to be both individualised and situated, in addition to expanding the public's view of hospices' role in death and dying.

Ethics

This research engages with and intervenes in current structures of ethics. It has gained ethical approval but moves beyond it by developing flexible and emergent

approaches to practice research. This research informs new approaches to ethics and integrity. The clinical supervision model used in art therapy supports interdisciplinary practice and engages in clinical contexts. These scaffolds give specialist knowledge and help to develop trust within these relationships. Schön (1983) expands the translatability of reflective practice across professions that use a student/supervisor model to navigate tricky situations. It develops a shared vocabulary and meaning that expands the validity of artistic methods within clinical settings and aims to develop a deeper understanding of the meaning of practices such as co-design or redesign (Bate and Robert, 2006). In addition to this expansion of ethical practice, this thesis suggests a reconsideration of the use of the term 'vulnerable' particularly in line with the use of co-design methods due to the power relations it instills (Ch.3, p.78). It acknowledges that exploring bereavement can expose and create emotional upheaval, but shows through the detailed narrative descriptions how collaboration, respect and care can empower people within these collaborations (Ch.5, p.128). The exhibition challenges the structures of ethical approval where experiences are reframed within a public setting. However, this does connect with people's values of the arts (Ch.4, p.99), where the arts promote an understanding of yourself and the world; challenging people's preconceptions by bringing beauty and increasing social engagement (Keaney et al's, 2007).

Co-Design

This research develops and expands an approach to co-design that is sited around the construction and exhibition of artefacts. It adds to a range of literature that focuses on designing with 'vulnerable' groups (Vines et al, 2014; Moncur et al, 2015) but expands this through focusing on how relationships, people and artefacts are formed through material engagement and making. This research responds to Kimbell's (2009) statement that a move towards design theory has created tension in the relationship between designers and things. By elaborating on the value of physical and digital things through 'gran's thimbles' (Ch.2, p.45) and exploring how these things extend social relationships, five design lenses are created that inform an in-tuned approach to working with collections and archives (Ch.2, p.69). This situates a process of engaging with materials and making that corresponds to Freda's, Sam's and Anne's experiences. This research complicates how things, people and materials entangle the designer and participant, guiding the artefact being produced into a live network of bodies, places, processes, materials, memory, concepts, continuing bonds and things. Within this network the boundaries between artefacts, structures and processes begin to break down

(Friedman and Stolterman, 2014) as the collaboration informs the fluid exchange between these modes of engagement. The home, which shifts between a situated studio and a space that holds their loved one's things, becomes a key player in the design process (Simonson et al, 2014). By reintegrating things they have in their homes into the conceptual development, the train book for example, they move from something that was designed and selected as a product to being functionally used within the co-design process confirming a person's life.

Art Therapy

This research provides a reflection for art therapists by exploring a process of making that works with people, things and sustained practice through material engagement. It extends the relationship that Moon (2010) identified between art therapy and material choice as an ethical negotiation. It uses co-design in conversation with practices in art therapy and bereavement literature to identify clients as collaborators within the therapeutic (Walter, 2009) and artistic processes (Moon, 2016). It expands current literature that aims to move art therapy towards a closer engagement with art, craft and design (Mahony, 2010; Moon, 2010; Rubin, 2016). Through the stories charting the participants' responses to the collaborative process, they are able to identify therapeutic experiences, despite the fact that this was not the intention of the research. The use of co-design allows for greater flexibility and agility in the process, which could inform new methodological approaches for art therapists who identify with the label of 'artist', as Elwin does within this research. By not recording the conversation in the sessions the focus is firmly placed on what is being produced through the collaboration. Crafting the artefacts informs the conversation and guides the collaborative exchange. In addition to this it sets up a structure for exhibiting as the result of such artistic inquiry. By working with the bereaved towards the pre-defined goal of exhibiting, a tangible ending can be ethically mediated, providing a ***rewarding and powerful*** end (Ch.5, p.141) to the collaboration.

Participants and Public Engagement

The journey that this research has taken to find and recruit the three participants has shown the challenges of bringing the bereaved into conversation with practice research, particularly when there is no fixed outcome. It throws up questions of confidence, trust, creativity and suitability as participants grapple with how they may fit into such projects. The relationship between the research and participants investigates artistic and design methods that are not widely understood within

medical settings and can be used to benefit communities that do not usually engage in research (Goodyear-Smith, 2015). In addition they provide moments of unparalleled inspiration and intuition that may sooth and help people through difficult times (Gunaratnam, 2007). It also works within current shifts in public understanding about the experience of bereavement (Ch.1, p.25) and supports the fact that talking and listening to people's stories can be helpful as an action in its own right (Gunartnam and Oliviere, 2009; Moncur et al, 2015). The participants' responses to the making process have been a delight to witness. Critical questions relating to aesthetics and labelling have emerged and allow the process to grow organically, informing the curatorial practice as collaboration. Although the participants have had different experiences and worked in different ways, they have all explored their relationship with someone who has died and found that this has produced surprising revelations about themselves. The locus of this project between people, things, stories, materials and making has prompted a more complex negotiation of constructing an artefact than traditional art therapy or co-design processes, and it is this complexity that makes it unique and individualised in the three collaborations. The participants have grown as makers through the use of studio practice, becoming collaborators over the two-year duration that puts them on an equal footing with practitioners. This allows the sessions to focus on the works produced and how we wish to frame them in the exhibition. Exhibiting helps develop a professional approach to the working relationship that is centred on making. For engaging in sensitive groups through co-design the relinquishing of control, in favour of flexibility, can be used to empower such collaborations.

Personal Reflections

Shifting to the personal it is undeniable that this research has been challenging. However, it is the challenges of this research that have been enlightening, surprising and deeply valuable for me as an early career researcher. I have discovered that what I value most within my research is a process that evolves naturally and does not enforce particular systems, goals or modes of practice on people. It is suited to design research that aims to 'meander' (Tellier, 2001: 21) through the processes, building in new approaches, methods and findings during design time. By "following the research… [and constructing it] through the collaboration" (App.5, p.226, line 488-491), it has also solidified the belief that it's important for "research today to take risks and to do things" that push the boundaries (line 499). By working with Anne, Freda, Sam and Elwin, my own understanding of bereavement has been pushed further. I am now placed to

initiate and mediate further interdisciplinary conversations around death, design and digital things uniting the materiality of co-crafted legacies in more depth and across different sites. One example is the curation developed around *Love After Death* for Nesta's *FutureFest*, September 2016, which has provided a test bed for the PhD and public engagement as well as future research.

Future Research – FutureFest

The *FutureFest*[80] curation (18th – 19th September 2016) comes chronologically at the end of this PhD. It is my PhD research (particularly drawing on chapters 1 and 2) but enacts a different form of public engagement to the final exhibition. The theme of *Love After Death* used the live creation of legacy agreements to investigate how *The Dead Body* and *Creative Bereavement* will be engaged with in future. It was based on current research and presented this as options for people's future legacy, such as digital memorial tattoos and live casting of funerals. It was inspired by processes of narrating the archive into something tangible (Ch.5, p.117). By enacting the material document of a legacy agreement as a mediating agent (to talk about) and writing/signing the document, this experience insights people to think more deeply about their own lives, their bodies and their loved ones, including how these may be extended or remediated in death. It also investigates the public's readiness in their relationship to the technological and social progression of death practices.

Figure 22: A collection of images documenting the *FutureFest*, *Love After Death* curation (2016). Top left: Exhibition of speculative design objects. Bottom right: a close up of one of the pages of the legacy agreement.

---

[80] FutureFest is Nesta's flagship public engagement event. It happens every 18 months and aims to attract between 3,000 – 5,000 members of the general public. The event allows practitioners to explore a 10 to 30 year horizon in their particular fields by imagining something currently marginal becoming a future mainstream, or by speculating on where certain strong trends may end up. Available at: http://www.futurefest.org/ [Accessed: 11th September 2016]

Through the use of consultations between members of the public and academics in the field of death and bereavement, it mediates and narrates each choice. The academics help to sensitively navigate this interaction and ethically care for those who choose to have this fifteen-minute experience. Those who did create a legacy agreement at *FutureFest* have additionally been asked if they can be contacted subsequently to talk about this experience. This will help to evaluate whether this form of short public engagement can have a lasting impact, giving people tools to rethink some of their current preconceptions about death.

Iteration and Scalability

I conclude with two important points around iteration and scalability. This research does not aim to replicate results or specific approaches for making with the bereaved. It pushes against general models that claim to represent humanity as a whole (Miller, 2010) but are detached from the specificities that create human nature (p.9). By using a collection of literature vignettes the design lenses are identified, which can be iterated and evolved within new mediums, sites, scales, situations and temporal structures (Simonsen, 2014; Barrett and Bolt, 2014). Using a blend of co-design and situated design, it shows how participants as collaborators can develop these research goals. Their collaboration shifts processes and research questions to tackle specific instances that occur at design time. Practice research also has the potential to be iterative through designing for specific sites, experiences and groups of people, as shown in the *Love After Death* curation. These designed experiences and processes are able to build collective knowledge that can be unified through writing, online documentation and live presentation (Gunartnam, 2007). Scalability can be used to adjust the level of interaction or the amount of people involved in the research. Through individual collaborations (Ch.5, p.143) this can be ethically expanded across different institutions or merged into already existing processes that engage with hospices such as service design or art therapy. This form of expansion and iteration shifts the practice into something distinct. It allows for specific forms of scaling and iteration that take into account the individualisation of death and bereavement (Ch.1, p.25). By considering each design intervention as a subtle shift in a particular network (Latour, 2008) that is impossible to predict, it is feasible to have deep engagement and collaborate, while gathering and exploring the relations of how these 'design events' (Tellier, 2011: 107) evolve specific research questions. Keeping in mind Gray's 1996 proposition that researchers predominantly use "methodologies and specific methods familiar to [them] as practitioners" (Gray, 1996: 3), it is not surprising to find practice researchers re-

purposing established methods through the use of interviews, reflective dialogue techniques, journals and observation to complement and enrich their design practices. In this evolving research dynamic we are witnessing an international maturing of the conceptual architecture of practice research and sharper clarity about the actual methods of practice research.

BIBLIOGRAPHY

Alfondy, S., (2007). *Neo-craft: modernity and the crafts*. The Press of the Nova Scotia College of Art and Design, Halifax Nova Scotia.

Andrews, M., Squire, C. and Tamboukou, M. eds., (2013). *Doing narrative research*. Sage.

Back, L. and Puwar, N., (2013). *Live methods*. Wiley-Blackwell.

Banks, R., (2011). *The future of looking back* (Vol. 67). Redmond/Washington, DC: Microsoft Press.

Barrett, E. and Bolt, B. eds., (2014). *Practice as research: Approaches to creative arts enquiry*. Ib Tauris.

Barthes, R., (1981). *Camera lucida: Reflections on photography*. Macmillan.

Bate, P. and Robert, G. (2006). Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Quality and Safety in Health Care*, 15(5), p.307-310. [Online]. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2565809/

Bell, C.G. and Gemmell, J., (2009). *Total recall: How the e-memory revolution will change everything*. Dutton.

Bellamy, C., Arnold, M., GIBBS, M., Nansen, B. and Kohn, T., (2013). Life beyond the timeline: creating and curating a digital legacy. In *CIRN Prato Community Informatics Conference* 2013: Refereed Paper.

Bonetti, R., (2008). Confronting images in motion: abɛbuu adekai and funerary practices among the Ga of Ghana, *Columbia University Academic Commons*. [Online]. Available: http://hdl.handle.net/10022/AC:P:10061.

Boomen, M., (2009). *Digital material: tracing new media in everyday life and technology*. Amsterdam University Press

Bowen, S., McSeveny, K., Lockley, E., Wolstenholme, D., Cobb, M. and Dearden, A., (2013). How was it for you? Experiences of participatory design in the UK health service. *CoDesign*, 9(4), p.230-246.

Bradwell, P. and Marr, S., (2008). *Making the most of collaboration: An international survey of public service co-design*. London: Demos.

Brubaker, J.R. and Hayes, G.R., (2011), March. We will never forget you [online]: an empirical investigation of post-mortem myspace comments. In *Proceedings of the ACM 2011 conference on Computer supported cooperative work* (p. 123-132). ACM.

Brubaker, J.R., Hayes, G.R. and Dourish, P., (2013). Beyond the grave: Facebook as a site for the expansion of death and mourning. *The Information Society*, 29(3), p.152-163.

Bush, V., (1945). As we may think. *The Atlantic Monthly*, 176(1), p.101-108.

Carter, P., (2004). *Material thinking: The theory and practice of creative research.* Melbourne University Publishing

Cross, N., (2001). Designerly ways of knowing: Design discipline versus design science. *Design issues*, 17(3), p.49-55.

Cross, N., (2006). *Designerly ways of knowing.* Springer-Verlag London.

Daniel, S., (2007). *The database: An aesthetics of dignity*. na: *1-40*. [Online], Available: http://artsites.ucsc.edu/sdaniel/publications_all/DBA_essay.pdf

Derrida, J., (1996*). Archive fever: A Freudian impression*. University of Chicago Press.

De Waal, E., (2011). *The hare with amber eyes*. Random House.

Dunne, A., Raby, F., (2013). *Speculative Everything: Design, Fiction, and Social Dreaming (MIT Press)*. 1st. The MIT Press.

Eagleman, D., (2009). *Sum: Forty tales from the afterlives*. Canongate Books.

Ehn, P., (2008), October. Participation in design things. In *Proceedings of the tenth anniversary conference on participatory design 2008* (p. 92-101). Indiana University.

Ellis Gray, S., (2012). The diversity of mourning practices online. *Digital Futures.*

Foucault, M., Martin, L.H., Gutman, H. and Hutton, P.H., (1988). *Technologies of the self: A seminar with Michel Foucault*. Univ of Massachusetts Press.

Frandsen, M.S. and Petersen, L.P., (2014). 'Urban Co-Creation'. In Simonsen, J., Svabo, C., Strandvad, S.M., Samson, K., Hertzum, M. and Hansen, O.E (eds) *Situated Design Methods*, MIT Press p.181.

Friedman, K and Stolterman, E. (2014). 'Series Foreword'. In Simonsen, J., Svabo, C., Strandvad, S.M., Samson, K., Hertzum, M. and Hansen, O.E (eds) *Situated Design Methods*. MIT Press.

Freud, S., (1922). Mourning and melancholia. *The Journal of Nervous and Mental Disease*, 56(5), p.543-545.

Garde-Hansen, J., (2009). MyMemories?: Personal digital archive fever and Facebook. In *Save as… Digital memories* (p.135-150). Palgrave Macmillan UK.

Galvin, M., (2013). So Who Is The Vulnerable One? *In Proceedings of CHI'13*, April 27 – May 2, 2013, Paris, France.

Gaver, B., Dunne, T. and Pacenti, E., (1999). Design: cultural probes. *Interactions*, 6(1), p.21-29.

Gell, A., (1998). *Art and agency: an anthropological theory*. Clarendon Press.

Getty, E., Cobb, J., Gabeler, M., Nelson, C., Weng, E. and Hancock, J., (2011), May. I said your name in an empty room: Grieving and continuing bonds on Facebook. In *Proceedings of the SIGCHI Conference on human factors in computing systems* (p. 997-1000). ACM.

Giaxoglou, K., (2014). "RIP man… u are missed and loved by many": entextualising moments of mourning on a Facebook Rest In Peace group site. *Thanatos*, 3(1), p.10-28.

Gibbs, M.R., Carter, M. and Mori, J., (2013). Vile Rat: Spontaneous Shrines in EVE Online. In *Workshop Proceedings of the 8th International Conference on the Foundations of Digital Games.* May (p. 14-17).

Glazzard, M., Kettley, R., Kettley, S., Walker, S., Lucas, R. and Bates, M., (2015). Facilitating a 'non-judgmental' skills-based co-design environment. In *Design4Health Conference*, July (p. 13-16). [Online]. Available: http://research.shu.ac.uk/design4health/wp-content/uploads/2015/07/D4H_Glazzard_et_al.pdf

Goffman, E., (1974). *Frame analysis: An essay on the organization of experience*. Harvard University Press.

Gombrich, E.H., (1979). *The sense of order: a study in the psychology of decorative art.* Phaidon Press.

Goodyear-Smith, F., Jackson, C. and Greenhalgh, T., (2015). Co-design and implementation research: challenges and solutions for ethics committees. *BMC medical ethics*, 16(1), p.1. [Online]. Available: http://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-015-0072-2

Gotved, S., (2014). Research Review: Death Online-Alive and Kicking!. *Thanatos*.

Gray, C. (1996) 'Inquiry through practice: developing appropriate research strategies' No Guru, No Method? *International Conference on Art and Design Research*, 4-6 September 1996, University of Art and Design Helsinki, Finland, [Online]. Available: http://carolegray.net/Papers%20PDFs/ngnm.pdf.

Gulotta, R., Odom, W., Forlizzi, J. and Faste, H., (2013), April. Digital artifacts as legacy: exploring the lifespan and value of digital data. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (p.1813-1822). ACM.

Gunaratnam, Y., (2007). Where is the love? Art, aesthetics and research. *Journal of Social Work Practice*, 21(3), p.271-287.

Gunaratnam, Y., (2009). Narrative interviews and research. *Narrative and stories in health care: Illness, dying and bereavement*, p.47-61. Oxford: Oxford University Press.

Gunaratnam, Y. and Oliviere, D. (2009). *Narrative and stories in health care: Illness, dying and bereavement.* Oxford: Oxford University Press.

Harris, M., (2008). *Grave matters: A journey through the modern funeral industry to a natural way of burial.* Simon and Schuster.

Harper, R., (2010). *Texture: human expression in the age of communications overload*. MIT Press.

Haverinen, A. (2014). *Memoria Virtualis: death and mourning rituals in online environments*. University of Turku: PhD thesis.

Hayles, N.K., (1999). *How we became posthuman: Virtual bodies in cybernetics, literature, and informatics.* University of Chicago Press.

Henare, A., Holbraad, M. and Wastell, S. eds., (2007). *Thinking through things: Theorising artefacts ethnographically*. Routledge.

Hillier, S., (1994). 'Working through objects', in Merewether, C. (ed.) 2006. *The Archive* (Whitechapel Documents of Contemporary Art).

Huss, E., (2010). 'Bedouin women's embroidery as female empowerment: Crafts as culturally embedded expression within art therapy'. In Moon, C (ed) *Materials and media in art therapy: Critical understandings of diverse artistic vocabularies*, p.215-229.

Ingold, T., (2013). *Making: Anthropology, archaeology, art and architecture*. Routledge.

Jacucci, G., (2004). Interaction as performance: Cases of configuring physical interfaces in mixed media. Doctoral Thesis, University of Oulu, Acta Universitatis Ouluensis.

Jefferies, J., 2012. Mangling practices: Writing reflections. *Journal of Writing in Creative Practice*, 5(1), p.73-84.

Jones, H., (2014). *Practicing awkward space in the city*. Goldsmiths, University of London: PhD Thesis

Karana, E., Giaccardi, E., Stamhuis, N. and Goossensen, J., (2016), June. The Tuning of Materials: A Designer's Journey. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems* (p. 619-631). ACM.

Kasket, E., (2012). Continuing bonds in the age of social networking: Facebook as a modern-day medium. *Bereavement Care*, 31(2), p.62-69.

Kimbell, L. and Street, P.E., (2009), September. Beyond design thinking: Design-as-practice and designs-in-practice. In *CRESC Conference, Manchester*. [Online]. Available: http://www.lucykimbell.com/stuff/CRESC_Kimbell_v3.pdf

Kirk, D. and Sellen, A., (2008). On human remains: Excavating the home archive. *Microsoft Research, Cambridge, UK.*

Klass, S. and Silverman, P., Nickman. S., eds, (1996). *Continuing bonds: New understandings of grief.* Taylor & Francis.

Klass, D. and Walter, T., (2001). 'Processes of grieving: How bonds are continued'. In Stroebe, M. S., Hansson, R. O., Stroebe, W., Schut, H., (eds). *Handbook of bereavement research: Consequences, coping, and care* (pp. 431-448). Washington, DC, US: American Psychological Association, xv, p. 814

Klass, D., (2006). Continuing conversation about continuing bonds. *Death studies*, 30(9), p.843-858.

Klastrup, L., (2015). "I didn't know her, but…": parasocial mourning of mediated deaths on Facebook RIP pages. *New Review of Hypermedia and Multimedia*, 21(1-2), p.146-164.

Lagerkvist, A., (2013). New memory cultures and death: Existential security in the digital memory ecology. *Thanatos*, 2(2), p.1-17.

Lagerkvist, A., (2016). Existential media: Toward a theorization of digital thrownness. *New Media & Society*, p.1-15.

Lange-Berndt, P. ed., (2015). *Materiality.* Co-published by Whitechapel Gallery and the MIT Press.

Latour, B., (1996). On actor-network theory: A few clarifications. *Soziale welt*, p.369-381.

Latour, B., (2004). Why has critique run out of steam? From matters of fact to matters of concern. *Critical inquiry*, 30(2), p.225-248.

Latour, B., (2005). *Reassembling the social: An introduction to actor-network-theory.* Oxford university press.

Latour, B., (2008). A cautious prometheus? A few steps toward a philosophy of design (with special attention to Peter Sloterdijk). In *Proceedings of the 2008 annual international conference of the design history society* (p. 2-10).

Law, J., (1992). Notes on the theory of the actor-network: Ordering, strategy, and heterogeneity. *Systems practice*, 5(4), p.379-393.

Lee, Y., (2008). Design participation tactics: the challenges and new roles for designers in the co-design process. *Co-Design*, 4(1), p.31-50.

Lister, S., Pushkar, D. and Connolly, K., 2008. Current bereavement theory: Implications for art therapy practice. *The Arts in Psychotherapy*, 35(4), p.245-250.

Lyman, P. and Kahle, B., (1998). Archiving digital cultural artifacts. *D-Lib Magazine*, 4(7).

Neisig, M., (2014). 'Transferring Methods to New Contexts'. In Simonsen, J., Svabo, C., Strandvad, S.M., Samson, K., Hertzum, M. and Hansen, O.E (eds) *Situated Design Methods*, MIT Press, p.357.

Mahony, J., (2001). Three commentaries: Looking experiences at three exhibitions. *International Journal of Art Therapy: Inscape*, 6(2), p.51-62.

Mahony, J (2010) *'reunion of broken parts' A therapist's personal art practice and its relationship to an NHS outpatient art psychotherapy group: an exploration through visual arts and crafts practice.* Goldsmiths, University of London: PhD Thesis.

Malafouris, L., (2013). *How things shape the mind.* MIT Press.

Marwit, S.J. and Klass, D., (1995). Grief and the role of the inner representation of the deceased. *Omega-Journal of Death and Dying*, 30(4), p.283-298.

Massimi, M. and Charise, A., (2009), April. Dying, death, and mortality: towards thanatosensitivity in HCI. In CHI'09 *Extended Abstracts on Human Factors in Computing Systems* (p.2459-2468). ACM.

Massimi, M., (2014). Stories from my thanatosensitive design process. *Interactions*, 21(1), p.47-49.

Mayer-Schönberger, V., (2011). *Delete: The virtue of forgetting in the digital age.* Princeton University Press.

McCarthy, J., Wright, P., Wallace, J. and Dearden, A., (2006). The experience of enchantment in human–computer interaction. *Personal and ubiquitous computing*, 10(6), p.369-378.

McCullough, M., (1998). *Abstracting craft: The practiced digital hand*. MIT press.

McGuinness, S., (2016). 'Lived Lives'. In Jefferies, J., Conroy, D, W., Clark, C, H., (eds). *The Handbook of Textile Culture*. Bloomsbury Academic.

Merewether, C., (2006). *The Archive* (Whitechapel Documents of Contemporary Art).

Miller, D., (2005). *Materiality*. Duke University Press.

Miller, D., (2008). *The comfort of things*. Polity.

Miller, D., (2010). *Stuff*. Polity.

Moncur, W., (2013), April. The emotional wellbeing of researchers: considerations for practice. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (p.1883-1890). ACM.

Moncur, W. and Kirk, D., (2014), June. An emergent framework for digital memorials. In *Proceedings of the 2014 conference on Designing interactive systems* (p.965-974). ACM.

Moncur, W., Julius, M., Van Den Hoven, E., and Kirk, D., (2015). Story Shell: the participatory design of a bespoke digital memorial. In *Proceedings of 4th Participatory Innovation Conference* (p.470-477).

Moon, C.H. ed., (2010). *Materials and media in art therapy: Critical understandings of diverse artistic vocabularies*. Routledge.

Moon, C.H., (2016). Relational Aesthetics and Art Therapy. In Rubin, J.A. (ed) *Approaches to Art Therapy: Theory and Technique*. Routledge.

Montu, A., (2007). 'Collection as a way of being', in Henare, A., Holbraad, M. and Wastell, S. (ed) *Thinking through things: Theorising artefacts ethnographically*. Routledge. Routledge.

Neimeyer, R.A., (2001). *Meaning reconstruction & the experience of loss*. American Psychological Association.

Neimeyer, R.A., Baldwin, S.A. and Gillies, J., (2006). Continuing bonds and reconstructing meaning: Mitigating complications in bereavement. *Death studies,* 30(8), p.715-738.

Neisig, M., (2014). 'Transferring Methods to New Contexts'. In Simonsen, J., Svabo, C., Strandvad, S.M., Samson, K., Hertzum, M. and Hansen, O.E (eds) *Situated Design Methods*, p.357. The MIT Press.

Nelson, R. (2013) *Practice as Research in Arts: Principles, Protocols, Pedagogies, and Resistances*. Hampshire; New York: Palgrave Macmillan.

Odom, W., Harper, R., Sellen, A., Kirk, D. and Banks, R., (2010), April. Passing on & putting to rest: understanding bereavement in the context of interactive technologies. In *Proceedings of the SIGCHI conference on Human Factors in computing systems* (p.1831-1840). ACM.

Odom, W., Banks, R., Kirk, D., Harper, R., Lindley, S. and Sellen, A., (2012), May. Technology heirlooms?: considerations for passing down and inheriting digital materials. In *Proceedings of the SIGCHI Conference on Human Factors in computing systems* (p.337-346). ACM.

Pitsillides, S., Katsikides, S., Conreen, M., (2009) Digital Death, IFIP WG9.5 In *Proceedings of the Virtuality and Society International Workshop on Images of Virtuality: Conceptualizations and Applications in Everyday Life*, April 23-24, Athens, Greece

Polanyi, M., (1966). *The Tacit Dimension*. Garden City, NY: Doubleday.

Poling, Jessica. (2015) *Pictures of Madness: Art therapy and Outsider Art's struggle for cultural authority*. [Online].
Available: http://hdl.handle.net/10066/16584.

Richardson, A., (2005). New media, new craft. In *Proceedings of the International Conference on Computer Graphics and Interactive Techniques* (p.157-159).

Riechers, A., (2012), May. My mourning junkie: Wailing at the Facebook wall. In *Workshop on Memento Mori: Held in conjunction with ACM SIGCHI 2012 in Austin, Texas* (Vol. 6).

Roberts, P., (1999). Tangible sorrow, virtual tributes: Cemeteries in cyberspace. *End of life issues: Interdisciplinary and multidimensional perspectives*, p.337-358.

Roberts, P., (2012). '2 people like this': Mourning according to format. *Bereavement Care*, 31(2), p.55-61.

Rubin, J.A. ed., (2016). *Approaches to art therapy: Theory and technique*. Routledge.

Sanders, E.B.N. and Stappers, P.J., (2008). Co-creation and the new landscapes of design. *Co*-design, 4(1), p.5-18.

Schlesinger, P. Selfe, M. and Munro, E., (2015) Curators of Cultural Enterprise: A Critical Analysis of a Creative Business, *Palgrave Macmillan*

Schön, A.D., (1983). *The Reflective Practitioner: How Professionals Think in Action*. Basic Books.

Sellen, A.J. and Whittaker, S., (2010). Beyond total capture: a constructive critique of lifelogging. *Communications of the ACM*, 53(5), p.70-77.

Shenk, D., (1998). *Data smog: Surviving the information glut.* Harper San Francisco.

Simonsen, J., Svabo, C., Strandvad, S.M., Samson, K., Hertzum, M. and Hansen, O.E., 2014. *Situated design methods*. MIT Press.

Sofka, C.J., (1997). Social support" internetworks," caskets for sale, and more: Thanatology and the information superhighway. *Death Studies*, 21(6), p.553-574.

Steedman, C., (2002). *Dust: the archive and cultural history*. Rutgers University Press.

Steen, M., (2013). Co-design as a process of joint inquiry and imagination. *Design Issues*, 29(2), p.16-28.

Strandvad, S.M., (2014). 'A Pragmatist Method for Situated Experience Design'. In, Simonsen, J., Svabo, C., Strandvad, S.M., Samson, K., Hertzum, M. and Hansen, O.E (eds) *Situated Design Methods*, p.279. The MIT Press.

Stroebe, M.S., Hansson, R.O., Schut, H. and Stroebe, W., (2008). Bereavement research: Contemporary perspectives. In *Handbook of bereavement research and practice: Advances in theory and intervention*. Eds: Stroebe, M.S., Hansson, R.O., Schut, H.E., Stroebe, W.E. and Van den Blink, E.I. American Psychological Association.

Taubert, M., Watts, G., Boland, J. and Radbruch, L., 2014. Palliative social media. *BMJ supportive & palliative care*, 4(1), p.13-18.

Telier, A., (Binder, T., De Michelis, G., Ehn, P., Jacucci, G., Linde, P. and Wagner, I., [81]) (2011). *Design Things*. The MIT Press.

Turilli, M. and Floridi, L., (2009). The ethics of information transparency. *Ethics and Information Technology*, 11(2), p.105-112.

Turkle, S., (2011). *Evocative objects: Things we think with*. MIT press.

Uriu, D., and Okude, N., (2010), August. ThanatoFenestra: photographic family altar supporting a ritual to pray for the deceased. In *Proceedings of the 8th ACM Conference on Designing Interactive Systems* (p.422-425). ACM.

Van Bekkum, J.E., Fergie, G.M. and Hilton, S., (2016). Health and medical research funding agencies' promotion of public engagement within research: a qualitative interview study exploring the United Kingdom context. *Health*

---

[81] These are a range of pseudonyms for the same writer, he/she uses each of these names in different cultures e.g. Pelle Ehn, in Copenhagen or Ina Wagner in Wien.

Research Policy and Systems, *14* (1). [Online]. Available: http://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-016-0093-4

Van Dijck, J., (2007). *Mediated memories in the digital age.* Stanford University Press.

Vines, J., McNaney, R., Lindsay, S., Wallace, J. and McCarthy, J., (2014). Special topic: Designing for and with vulnerable people. *interactions*, 21(1), p.44 – 46.

Wallace, J. and Press, M., (2004). All this useless beauty: the case for craft practice in design for a digital age. *The Design Journal*, 7(2), p.42 – 53.

Wallace, J. (2007). *Emotionally charged: A practice-centerd enquiry of digital jewellery and personal emotional significance.* Sheffield Hallam University: PhD Thesis.

Walter, T., (1996). A new model of grief: Bereavement and biography. *Mortality*, 1(1), p.7–25

Walter, T., (2008). The presence of the dead in society. In *Conference on Death & Dying in 18-21c Europe*, Alba Iulia, Romania.

Walter, T. (2009). Mediator Deathwork. In: Y. Gunaratnam and D. Oliviere, ed., *Narrative and* stories in health care, 1st ed. Oxford: Oxford University Press.

Walter, T., Hourizi, R., Moncur, W. and Pitsillides, S., (2012). Does the internet change how we die and mourn? Overview and analysis. *OMEGA-Journal of Death and Dying*, 64(4), p.275-302.

Walter, T. (2013) Do modern societies comprise the dead as well as the living? CDAS Working Paper Series – CDAS-001-0113. [Online] Available: http://www.bath.ac.uk/cdas/documents/cdas_working_paper_cdas-001-0113.pdf

Walter, T., (2015). Communication media and the dead: From the stone age to facebook. *Mortality*, 20(3), p.215-232.

Westwood, J., (2013). Hybrid Creatures: Mapping the emerging shape of art therapy education in Australia, including reflections on New Zealand and Singapore (Forthcoming). *Australia and New Zealand Journal of Art Therapy*, p. 1-15.

Westwood, J., (2014). Finding a voice, making your mark (International Art Therapy Conference Exhibition), Goldsmiths, University of London.

Woodhead, L., (2016). Intensified Religious Pluralism and De-differentiation: the British Example. *Society*, 53(1), p.41-46.

Yi, C., (2010). 'From Imperfect to I Am Perfect'. In Moon, C (ed) *Materials and media in art therapy: Critical understandings of diverse artistic vocabularies*, p.103–117.

APPENDIX 1: PUBLIC OUTPUT

This section includes a range of publications and events that I have developed as part of the process of my PhD. Some of this writing has come to form specific sections of this thesis:

The section on Legacy and Context (Ch.1, p.34) is drawn from the conference paper *Transcending the Archive: Reflections on Online Identity and Death* (2012). Some thoughts in the Speculative Design and Research section (Ch.1, p.37) stem from my *Review of The Future of Looking Back* (2012) for Mortality Journal. Additionally some of the content in Chapter 2 on Technological Things as Mediators (p.43) is drawn from the final section of the book chapter *Narrating the Digital: The Evolving Memento Mori* (2013).

Editor

Special issue for the Journal of Broadcasting and Electronic Media.

K. Giaxoglou, K. Döveling and S. Pitsillides (2017) *Networked Emotions: Interdisciplinary Perspectives on Sharing Loss Online*, Journal of Broadcasting & Electronic Media, 61:1, 1-10, DOI: 10.1080/08838151.2016.1273927.

Chapters in Edited Volumes

S. Pitsillides (2016) *Death and Memory in the 21st Century.* Memory in the Twenty-First Century: New Critical Perspectives from the Arts, Humanities, and Sciences. Groes, S. (Ed.) Publisher: Palgrave Macmillan UK

S. Pitsillides, J. Jefferies (2013) *Narrating the Digital: The Evolving Memento Mori.* Digital Legacy and Interaction: Post-Mortem Issues, Computer-Human Interaction Series Maciel, C & Pereira, V. C. (Eds.), Publisher: Springer

S. Pitsillides, M. Waller, D. Fairfax, (2013) *Digital Death, the Role Data Plays in how we are (Re)membered*. Digital Identity and Social Media, S. Hatzipanagos and Dr S. Warburton (Eds), Publisher: IGI Global

S. Pitsillides, M. Conreen, J. Jefferies, (2012) *Museums of the Self and Digital Death: An Emerging Curatorial Dilemma for Digital Heritage*, Heritage Matters: Understanding and Experiencing Heritage Through Social Media, Giaccardi, E (ed.). Publisher: Routledge

Journal Papers & Reviews

S. Pitsillides (2012) Review of The Future of Looking Back, Richard Banks, Microsoft Press, Oct 2011 for *Mortality Journal*. Volume 17, Issue 1

T. Walter, R. Hourizi, W. Moncur, S. Pitsillides (2011) Does the internet change how we die and mourn? Overview and analysis, *Omega: Journal of Death & Dying*, 64 (4), pp. 275-302

S. Pitsillides. (2011) Review of Save As… Digital Memories, Joanne Garde-Hansen, Andrew Hoskins and Anna Reading, Hampshire: Palgrave Macmillan, 2009 for the *International Journal of Performance Arts and Digital Media*, Volume 7, Number 1, 1 March 2011. pp. 117-122(6)

Conference Papers (Published in Proceedings)

S. Pitsillides, J. Jefferies (2016) Intimate Technologies: The Ethics of Simulated Relationships. Proceedings of the 22nd International Symposium on Electronic Art, ISEA2016, Hong Kong

A. Maragiannis, J. Jefferies, S. Pitsillides, G. Boddington (2016) Can non-anthropocentric relationships lead to true intimacy with technology? Proceedings of the 22nd International Symposium on Electronic Art, ISEA2016, Hong Kong

B. Psarras, S. Pitsillides, A. Maragiannis (2013) Dérive in the Digital Grid, Breaking the Search to get Lost, Proceedings of the 19th International Symposium on Electronic Art, ISEA2013, Sydney

J. Jefferies, A. Maragiannis, S. Pitsillides, M. Velonaki (2013) Mirroring Sherry Turkle: A Discussion on Authenticity, Humanity and Technology, Proceedings of the 19th International Symposium on Electronic Art, ISEA2013, Sydney

S. Pitsillides (2012) Transcending the Archive: Reflections on Online Identity and Death, CHI Extended Abstracts, Momemto Mori: Technology Design for the End of Life. Austin, Texas. USA

S. Pitsillides, S. Katsikides, M. Conreen (2009) Digital Death, IFIP WG9.5 Virtuality and Society International Workshop on Images of Virtuality: Conceptualizations and Applications in Everyday Life, April 23-24, Athens, Greece

Organising Conferences, Unconferences & Workshops

16th May 2017   Material Legacies: Death, Design and the Digital
Lecture. Part of the Death and Dying Research
Seminar Series. Open University.

11th Jan 2017   Death and Design in the 21st Centaury. Briefing
lecture for The Augmented Death for MA design
courses (Industrial Design, Material Futures and
Design by Project). Central Saint Martins.

20th July 2016   Feminism, Policy and Otherness Panel as part of
Creative Conversations Research Group.

17th – 18th August 2015   Co-Convenor of the 2nd international Death Online
Research Symposium

24th July – 26th July 2015   Co-Convenor of Material Environments: Sensing
Time and Matter in Digital and Visual
Culture Conference. Sponsored by TiMaDi Research
Group

14th May – 28th May 2015   Co-facilitator Haptic Narratives | Textural exploration
in film Seminar Series. Sponsored by TiMaDi
Research Group on the following dates:

                                     14 May 2015 - Touching Sounds through the Screen

                                     21 May 2015 - Embodied and Remembered
Experiences

                                     28 May 2015- Political Dimensions and Felt Values

31st Aug – 3rd Sep 2014   Associate Convener of DRHA2014, Digitial Research
in Humanities and the Arts Conference

20th May 2014   Communication Futures: Embracing Emotional
Design and Haptics, MA Interaction Design/ MA
Industrial Design Workshop, TUDelft

6th Oct 2012   Convenor for Digital Death Day: London

| 11th Nov 2011 | Convenor for Digital Death Day: Amsterdam in collaboration with the Tropenmuseum's Death Matters Exhibition |
| 9th Oct 2010 | Convenor for Digital Death Day: London |

Public Engagement

12th May 2017	Chair for two panels as part of Croydon's Dying Matters Week on Creating Narratives about Dying Matters - culturally, artistically, digitally in collaboration with St Christopher's Hospice that aimed to engage the local community with questions of death and diversity.
7th April 1017	Speaker at the Edinburgh International Science Festival. On the A Death Online panel.
15th Mar 2017	Panel on Designing Death: Challenges and Aesthetics for the 21st Century. Drawing together expertise from Death Studies, Design, the Hospice sector and Creative Bereavement, this served as an extension of debates explored through the Material Legacies exhibition.
5th Mar 2017	Speaker at the Southbank Centre's Beyond Belief festival on the The Way to Immortality: Technology and Transcendence panel.
28th Feb – 25th Mar 2017	Curator, Material Legacies. Exhibition of works created for the Stephen Laurence Gallery as a PhD research outcome with participants from The Hospice of St Francis. This research is in association with the University of Greenwich (Creative Professions and Digital Art) and has been supported by The Hospice of St Francis and Goldsmiths, University of London.
15th Oct 2016	Speaker at Life.Death.Whatever exhibition at National Trust's Sutton House.
17th – 18th Sept 2016	Curator and concept development for the future of Love after Death, as part of the FutureLove theme at

	FutureFest. Commissioned by NESTA and supported by the University of Greenwich.
18th July 2015	Co-facilitator, Making London. A co-design methodologies workshop involving local charities, design and tech industry members, academics et al. Sponsored by Creative Conversations Research Group in collaboration with the XDs (Experience Design Group).
14th Nov 2013	Speaker at Night of the Digital Dead, Internet Week Europe
4th Oct 2013	Part of the Panel, Re-Wired: Memory in the Digital Age, The Memory Network AHRC Project, The Times Cheltenham Literature Festival
28th Jan 2012	Speaker at Death: The Southbank Centre's Festival for the Living

Online Dissemination

Project Website: http://www.digitaldeath.eu/

Twitter Page: http://twitter.com/RestInPixels (@RestInPixels)

Creative Conversations: http://blogs.gre.ac.uk/creativeconversations/ (Public Engagement and Research Group)

APPENDIX 2: ETHICAL PRACTICE

Ethical approval forms from the Design Department at Goldsmiths [V2]

An adapted version of the first version to include changes e.g. hospice to home.

DEPARTMENT OF DESIGN

Research and Enterprise Committee

RESEARCH ETHICS APPROVAL FORM (Staff and students)

This form should be completed for any research project that involves human participants or if the research involves animals or if it may involve environmental harm. The principal investigator or, where the principal investigator is a student, the supervisor, is responsible for exercising appropriate professional overview of the research.

You should:
- first, read and understand the Goldsmiths Code of Practice on Research Ethics: http://www.gold.ac.uk/media/research-ethics.pdf
- then complete and submit this form
- then, wait for approval before contacting any potential participants in any research.

Section One   Applicant Details

1.1 Name of researcher	Stacey Pitsillides
1.2 Status (undergraduate student, postgraduate student, staff)	Postgraduate
1.3 Email address	stacey.pitsillides@gmail.com / dt602sp@gold.ac.uk
1.4 Contact address	7 Piano Studios, 2 Belmont Hill, Lewisham, London, SE13 5BF
1.5 Contact phone number	07972183552

Section Two   For students only

2.1 Programme	PhD in Design
2.2 Course	N/A
2.3 Your supervisor or course leader's name	Martin Conreen (1st) Janis Jefferies (2nd)
2.4 Your email address (if different from above)	
2.5 Your contact address (if different from above)	

Section Three   Project Details

3.1 Project title: Crafting the Archive: Creative Responses to Digital Remains
3.2 *Brief* outline of the project, including its purpose: This project aims to work with bereaved clients from St Francis Hospice who have a large unmanageable digital archive of a lost loved one's personal data. The project seeks to set up collaborations between practitioners (practise based arts psychotherapists and designers) and bereaved clients to allow clients a space for personal reflection on the context and value of the digital data left behind. This will manifest through a series of workshops which aim to work through the archive creatively where the clients role will be to discuss the parts of the archive most valuable to them and practitioners role to use their own creative practises to co-construct an artefact (digital or otherwise) from the tacit descriptions and conversation with their client. This system of personal relationships and conversation as an instigator for creativity aims to use a metadesign and crafting approach to the archive. To clarify this, the concept of crafting

(within this proposal) refers to the ability of both individuals (participant and practitioner) to rely on the tacit judgments and concepts occurring through natural conversation while forming the artefact. This emphasis on individual partnerships, conversation and understanding within this study, helps to develop a crafting approach to the archive whereby there is no fixed process or outcome.

3.3 *Brief* description of methods of data collection:

The predominant method for data collection within this study will be through filmed interviews, which will transcribed and analysed thematically. These interviews will take place after the project has been completed as a reflection on both the artefact produced and the process of co-creating.

3.4 Where will the data collection be undertaken? St Francis Hospice

Section Four   Human participants

| 4.1 How many and what type of participants are involved in the research? |
| Ten participants will be involved, five bereavement clients (participants), four arts psychotherapists and myself (practitioners) |
| *If NIL go to Section Seven. Otherwise, complete this Section.* |

| 4.2 How will the participant(s) be recruited? *(Attach copies of any recruiting materials if used).* |
| The participants will be recruited with the help of St Francis hospice using directed flyering within the network of the hospice. The practitioners will be trained art psychotherapists who have a strong personal practice that they would like to explore with the participants. This is important within the pilot study as it limits the risk to both parties (participants and practitioners) and will be far more manageable within the realms of this Case Study. Practitioners will be recruited in both a targeted approach (of sending an e-vite to already potentially interested parties) and through considering targeted arts psychotherapy events and online portals to widen recruitment if necessary e.g. Creative Response http://www.creativeresponse.org.uk/ & the British Association of Art Therapists (BAAT): http://www.baat.org/. |

| 4.3 How will the participant(s) consent be obtained? *(Include a copy of any proposed consent form).* |
| There are detailed information and consent forms attached which explain the process of giving consent clearly and aim to answer a range of questions prior to the participant agreeing to take part in the study. |

	Insert ➡	Y	N
4.4 Will it be necessary for participants to take part in the study without their knowledge and consent at the time? (e.g. covert observation of people in non-public places)			✓
4.5 Is there any deception involved?			✓
4.6 Will the participant(s) be paid or rewarded?			✓
4.7 Will the participant(s) be fully informed about the nature of the project and of what they will be required to do? (*Attach any associated materials.)*		✓	
4.8 Will the participant(s) be told they can, if they wish, withdraw from participation at any time? (*Attach any associated materials.)*		✓	
4.9 If you have ticked a box marked * please give the question number/s and fuller information here:			

Section Five   Persons who are young, vulnerable or in legal custody

	Insert ➡	Y	N
5.1 Will any young persons (under the age of 18 years), vulnerable persons (e.g. with learning difficulties or with severe cognitive disability), or those in legal custody be involved in the research? *If NO, go to Section Six. If YES please complete this section.*			✓
5.2 How will consent be given (i.e. from the participant themselves or from a third party such as a parent or guardian) and how will agreement to the research be asked for? *(Attach any associated materials.)*			

	Insert ➡	Y	N
5.3 If you are conducting research with young persons under the age of 18 years or 'vulnerable persons' do you have Criminal Records Bureau clearance? *(Please attach evidence of such clearance.)*			
5.4 Will face-to-face interviews or observations or experiments be overseen by a third party (such as a teacher, care worker or prison officer)?		*	
5.5 Is it possible that the research might disclose information regarding child sexual abuse or neglect? *(If*		*	

yes, indicate how such information will be passed to the relevant authorities (e.g. social workers, police), but also indicate how participants will be informed about the handling of such information were disclosure of this kind to occur. A warning to this effect must be included in the consent form if such disclosure is likely to occur.)		
5.6 If you have ticked a box marked * please give the question number/s and fuller information here:		

Section Six Participants' personal data

	Insert ➤	Y	N
6.1 Will personal data of any kind (including digital and images) be gathered on participants?		✓	
If NO go to Section Seven. If YES, complete this Section.			
6.2 Will the data be anonymous?		✓	✓
6.3 Will the data be treated confidentially?		✓	
6.4 Will the study involve discussion of topics sensitive to the participants (e.g. religious or culturally sensitive issues, sexual activity, drug use)?			✓

6.5 How long will the data be stored and how will it be eventually destroyed?
The information collected from participants and practitioners during this study will be kept confidential. Their name and details will only be known to me. The complete recordings will be stored securely and only I will have access to them. Their recorded interview will not be stored or transported in unsecured areas such as the internet, email or other organisations computers. Information that could identify them will be kept separate from the recordings. Digital interview recordings, notes and other related electronic data will be stored on computers that are password protected. All data storage and use will comply with the Data Protection Act (1998) and kept by the Principal Investigator for 7 years, after which all the video recordings and interview transcripts will be destroyed (shredded).

6.6 If you have ticked a box marked * please give the question number/s and fuller information here:

6.2: Y & N / 6.3: Y
The participants and practitioners will be recruited with prior consent to the use of some selected data and video or audio footage from their interviews within a final exhibition of this project. It will be made clear that they may be recognised from their voice or image within this footage. There will of course be an opt-out policy, which participants can use at any point within the process written into the consent form and additionally a second option for use of anonymous data only.

Section Seven Risk and Duty of Care issues

	Insert ➤	Y	N
7.1 Will the research involve the investigation of illegal conduct?			✓
7.2 Are there any potential adverse consequences to the participant(s), or any other person?		✓	
7.3 Are there any procedures which may cause discomfort, distress or harm to the participant(s), or any other person?		✓	
7.4 Will the research place you in situations of harm, injury or criminality?			✓
7.5 Have you any special personal considerations or vulnerabilities that might influence your safety while carrying out fieldwork (injuries, disabilities, allergies, asthma, personal conflicts with informants/community etc.).			✓
7.6 Might the research cause harm to those represented in it?			✓
7.7 Will the research involve any animal subjects?			✓
7.8 Will the research cause any environmental harm?			✓
7.9 Are drugs, placebos or other substances (e.g. food substances, vitamins) to be administered to the study participants or will the study involve invasive, intrusive or potentially harmful procedures of any kind?			✓
7.10 Will blood or tissue samples be obtained from participants?			✓

7.11 Is pain or more than mild discomfort likely to result from the study?		✓
7.12 Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?	✓	
7.13 Will the study involve prolonged or repetitive testing?		✓
7.14 Do you know of any other potential developments arising from this research that may lead to ethical, health, safety, risk, harm, or duty of care concerns?		✓

7.15   If you have ticked a box marked * please give the question number/s and fuller information here:

7.2/ 7.3: Y
There is the potential that the process of discussing bereavement could be emotionally painful for participants. They are of course free to stop the process at any time, however through the support of myself and the team at St Francis we aim to focus the study on positively remembering and celebrating the deceased. Some participants and practitioners may also find the process of collaboration frustrating, however as the process is flexible the particular roles and processes of the participant and practitioner can be renegotiated at any time to find a better arrangement for moving forward.

7.12: Y
It is obvious that when dealing so directly with the topic of bereavement, there is always the possibility of discomfort, distress or harm to the participants but I believe that this is significantly limited by the strong support network operated at St Francis, with sessions being overseen by psychotherapist and Hospice Director Kimberley McLaughlin and all practitioners (other then myself) having a background in Arts Psychotherapy.

Section Eight   **Other matters**

	Insert ➡	Y	N
8.1 Are there any conflicts of interest regarding the investigation and dissemination of the research (e.g. with regard to compromising independence or objectivity due to financial gain)?			✓
8.2 Is the research likely to have any negative impact on the academic status or reputation of the College?			✓
8.3 Is data to be collected from an institutional location (such as a school, prison, hospital)? *If so, attach evidence of agreement obtained from the relevant authority (e.g. Head Teacher, Local Education Authority, Home Office)?*		✓	
8.4 If you have ticked a box marked * please give the question number/s and fuller information here:			

Section Nine   **Attachments, signatures and submission**

Wherever possible, applications will be dealt with within two weeks of receipt. Delays will occur if the application has not been carefully completed. The decision regarding your application for ethical approval will be communicated to you and your supervisor (if applicable) directly.

You should now complete the following checklist, supply any necessary signatures and submit the full application/documentation to the Department Research and Enterprise Committee Chair/Department Ethics Office via the Design Office.

9.1   Attachment checklist:
Have you attached copies of all supporting materials? Please indicate which and insert ➡ in the appropriate column

Document	Not applicable	Attached

Recruitment document/s		✓
Informed consent		✓
Other information for participants		✓
Consent agreements for young, vulnerable or 'in custody' persons	✓	
Criminal Records Bureau clearance	✓	
Institutional location agreement		✓
Other *(please specify)...*		

9.2   To be completed by student applicants…

Please note that your Supervisor and the Department Research and Enterprise Committee Chair/Department Ethics Officer should be notified of any adverse or unforeseen circumstances arising out of this study. If there are significant changes to the research design regarding research ethics, please notify the Committee immediately.

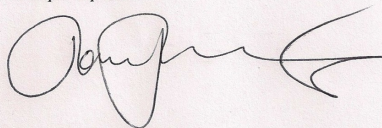Signature of Applicant   Date 16.10.2013

9.3 To be completed by Principal Supervisor…

Please note that the Department Research Ethics Committee Chair/Department Ethics Officer should be notified of any adverse or unforeseen circumstances arising out of this study or of any emerging ethical concerns that the Supervisor may have about the research once it has commenced.

	Insert ➔	Y	N
Has the student read and understood the Goldsmiths Code of Practice on Research Ethics?			
Has there been appropriate discussion of the ethical implications of the research with you as Supervisor?			
Are the ethical implications of the proposed research adequately described in this application?			
Please add any other comments you wish to make here:			

Signature of Principal Supervisor   Date

16/10/2013

10 Statement of Ethical Approval

This project has been considered using agreed Departmental procedures and is now approved. This approval is valid for a maximum period of _2_ year/s.

Signed   Date

Print Name

Department Research Ethics Committee Chair/Department Ethics Officer

Design: R&E Ethics 2013v4

Letter of approval from the Ethics Sub-Committee at Goldsmiths

Goldsmiths

UNIVERSITY OF LONDON

Research Ethics Sub-Committee

Approval Status: Approved

To:	Ms. S. Pitsillides
From:	Prof. C. French
CC:	Dr. M Swijghuisen Reigersberg
Date:	29th September 2014
Ref:	EA 1192

We are pleased to inform you that the Research Ethics Sub-Committee has approved your project: **Crafting the Archive: Creative Responses to Digital Remains.**

Approved ethical applications are available in the Research Office for other researchers in the college who are applying for grants; they may also be sent out as email attachments if requested. This is to help applicants. Please let Emmy Gregory know within two weeks of this letter if you would rather not have your ethical application form available in this way. Many thanks.

Dr Muriel Swijghuisen Reigersberg
Secretary,
Research Ethics Committee

pp.

Prof. Christopher French, chair

The Hospice of St Francis Project Registration Form

The Hospice of St. Francis, Berkhamsted.

Appendix One: CLINICAL AUDIT, SERVICE EVALUATION OR RESEARCH PROJECT REGISTRATION FORM

After completion, please return to Barbara Miller in the Education and Research Team

PART A –Registration – ALL RESEARCH, CLINICAL AUDIT AND SERVICE EVALUATION PROJECTS

A1.Project Title CRAFTING THE ARCHIVE: CREATIVE RESPONSES TO DIGITAL REMAINS

A2.Project Team Members

Project Lead STACEY PITSILLIDES

Contact E Mail & Tel No: stacey.pitsillides @ gmail.com

Job Title PhD CANDIDATE

Department DESIGN 07972183352
spits009@gold.ac.uk

Other project members names and emails:
JANIS JEFFERIES
j.jefferies@gold.ac.uk

A3. Audit & Service Evaluation Project discussed with by Clinical Audit Facilitator   Yes _   No _

Research Projects discussed with Director of Education & Research   Yes _   No _

Date Discussed:

A4.Project Details

Project Question: Can we help berieved patients find meaning and creativity in their lost loved ones digital data?

Is the project multi-professional? Yes ✓ No _

Give details: Working with four art psychotherapists

Why was the topic selected (please, tick all that apply):

Academic course _   High frequency of events _   High cost _   High risk issue _

Perceived problem area _   National requirement _   Repeat audit/evaluation _

Other reason (please state) academic research

Standard for the audit/service evaluation: (please, tick all that apply)

NICE Guidance _   National Guidelines _   Royal College Guidelines _   Hospice Guidelines
_

Specialist professional society guidelines _   Other standard(s) _ (state which)

Please give references for the standard(s)

Are patients or carers to be involved in the project?   Yes ✓ No _

In the planning stage ✓   As a part of the data collection method ✓

Other (please state) the workshops conducted will invole berieved clients.

Is ethical approval applicable?   Yes ✓ No _

If yes please provide evidence of approval with this registration form

Expected start date of project: this cannot be accuratly predicted due to the complications of recruitment   Expected completion date of project: 03/15

A5.Project Lead:

I agree to adhere to Data Protection Act and Caldicott principles during all stages of the project, to submit to the Director of Education and research, on the project completion, project summary in approved format together with data collection form/questionnaire. I also agree that the approved project summary will be

Research, Clinical Audit and Service Evaluation Policy	
	Revision Number: 4
Ref: D084	Date of Implementation: 13/05/2010
Page 1 of 3	Review due by: May 2014

The Hospice of St. Francis, Berkhamsted.

included in Hospice reports, published on Hospice Intranet and made available to the public under the Freedom of Information Act.

SIGNATURE..........*Steny*.......................... DATE..30/01/14.....................

Now please complete Part B

PART B – Project Methodology/Methods Details

B.1 –Project methodology

(If you are not sure about the following, Audit or Research Lead will help you decide)

1. **Data collection will be:**

   Prospective _   Retrospective _   Serial _   Other (please state) ✓
   (present)   (past)   (Ongoing)   *Data will be collected in the*
                                                                     form of AmI interviews.

2. **Data will be obtained from:**

   Case notes   Electronic databases _   Questionnaires _

   Interviews ✓   Focus groups _   Other (please state)

3. **Sample details:**

   e.g. Diagnosis / Condition / Procedure/intervention

   Expected sample size in total   5

B.2 – Project support agreement

Project Lead

I agree:

1. To adhere to Data Protection Act and Caldicott principles during all stages of clinical audit project.

2. To inform Education and Research Dept about any amendments to the project data collection form/questionnaire made during the course of the project.

3. To provide a summary report for the Clinical Care Committee, or Education and Clinical Audit Lead

4. To inform Education and Research Department about presentation/publication of project results.

5. That the final, approved Project Report Summary will be included in Hospice of St Francis reports, published on Intranet and made available to public under the Freedom of Information Act.

Signature ....*Steny*................................   Date .....30/01/14.......................

Thank you for completing this form.
Please now return to Sarah Russell/Barbara Miller
Hospice of St Francis, Spring Garden Lane, Off Shootersway, Berkhamsted, Herts HP4 3GW: 01442 869550
Sarah.russell@stfrancis.org.uk or Barbara.miller@stfrancis.org.uk

Office use only

Research, Clinical Audit and Service Evaluation Policy	
	Revision Number: 4
Ref: D084	Date of Implementation: 13/05/2010
Page 2 of 3	Review due by: May 2014

Disclosure and Barring Service Certificate

Certificate Number	001456832420
Date of Issue:	29 AUGUST 2014

Applicant Personal Details

Surname: PITSILLIDES

Forename(s): STACEY OLGA

Other Names: NONE DECLARED

Date of Birth: 26 MAY 1986

Place of Birth: MELBOURNE AUSTRALIA

Gender: FEMALE

Employment Details

Position applied for:
ADULT WORKFORCE HOSPICE BEREAVEMENT SUPPORT

Name of Employer:
THE HOSPICE OF ST FRANCIS

Countersignatory Details

Registered Person/Body:
CRB DISCLOSURE SERVICES LTD T/AS DISCLOSURE SERVICES

Countersignatory:
JANET SMITH

Police Records of Convictions, Cautions, Reprimands and Warnings

NONE RECORDED

Information from the list held under Section 142 of the Education Act 2002

NOT REQUESTED

DBS Children's Barred List information

NOT REQUESTED

DBS Adults' Barred List information

NONE RECORDED

Other relevant information disclosed at the Chief Police Officer(s) discretion

NONE RECORDED

Enhanced Certificate

This document is an Enhanced Criminal Record Certificate within the meaning of sections 113B and 116 of the Police Act 1997.

THIS CERTIFICATE IS NOT EVIDENCE OF IDENTITY

DBS Disclosure and Barring Service, PO Box 165, Liverpool, L69 3JD Helpline: 0870 90 90 811 © Crown Copyright

Letters of acceptance from the Hospice of St Francis

Stacey Pitsillides
PhD Candidate
Goldsmiths
University of London
25 St James
New Cross SE14 6NW

13th August 2014

Dear Stacey,

Re: Art Memorial Project at the Hospice of St Francis: Hospice of St Francis Research No:06/14

Thank you for your documentation and correspondence regarding commencing the above research project at St Francis. We are pleased and excited about taking this forward with you.

I confirm that approval has been given to you under the following context:

1. You have confirmed University Ethics approval – and have given us a copy of this (dated 16/10/2013)
2. You have completed and agreed to our research application process including reporting back to us your findings (dated 30/01/14)
3. You have discussed and agreed with Tania Brocklehurst and Kimberley McLaughlin the recruitment process (as per meeting of 23/06/14)
4. You have discussed and agreed with Gillian Van de Mere the DBS process for your volunteer art therapist – as per emails of 7/08 2014

For day to day queries re recruitment please liaise with Tania and Kimberley as necessary

For queries about the research process please liaise with Barbara Miller.

Good luck with your research – it sounds a project that can really make a difference to care and theory.

With best wishes

Yours sincerely,

Sarah Russell

Sarah Russell: Director of Education and Research, Hospice of St Francis and Peace Hospice Care

Cc; Barbara Miller, Gillian Van der Merwe, Tania Brocklehurst, Kimberley McLaughlin Ros Taylor,

Stacey Pitsillides
3 Colls Road,
Southwark,
London SE15 2NS

1st May 2013

Dear Stacey

Re: DIGITAL DEATH, REMEMBERING WHAT IS LEFT ONLINE: A Reflective Study on the Creative Crafting of Digital Archives

Thank you for approaching the Hospice of St Francis to be a research site for the above study.

I confirm that we would be very happy for the Hospice of St Francis to take part in the pilot as detailed in your project summary under the following conditions:

1. A completed Hospice of St Francis Research Registration form (as attached)
2. For our records: Confirmation of and a copy of your ethic committee approval
3. Also copies of your ethics committee approved invitation to take part, project plan, information sheet, consent form and other relevant documentation or literature
4. Clarity in the consent form about the use of words, images and crafted work - and if it is only for research purposes and/or if can be used for dissemination and publication
5. Planned start and stop timeline for the pilot study
6. Five participants (recruited from St Francis Hospice) and five practitioners (including yourself)
7. How you will feed back to the hospice the results of the research so that it will benefit the hospice community as well as contributing to the wider body of knowledge
8. Clarification about managing anyone who might be distressed

We are very much looking forward to taking part in this project with you.

Yours sincerely

Sarah Russell
Doctoral Research Student
MSc, PG(Dip), BA(Hons), RGN
Director of Clinical Education and Research

cc: Dr Ros Taylor, Kimberley McLaughlin

Recruitment Flyers [V1, 2, 3]

I

2

3

Recruitment Letter to the Bereavement Team at the Hospice of St Francis

In Memory of their Digital Lives

Research Project

Hello, my name is Stacey Pitsillides and I am a PhD Candidate in Design at Goldsmiths, University of London. I am working in collaboration with The Hospice of St Francis on the main case study for my PhD thesis.

I am contacting you to help extend the word of mouth about my project and recruit people for my study. The study will work with a small group of people in a series of four one-to-one sessions with a team of Creative Practitioners. These sessions would be focused on helping these people to reflect on and consider the meaning behind their loved one's digital lives. This could include their Facebook page, digital photographs, online music collections, e-mails and others. The first couple of sessions would focus on talking about these separate parts of their digital life and building them into a digital life story. The latter sessions would aim to create a personal memory object that creatively reflects and celebrates their loved one's digital life. The sessions would take place where possible at the person's own home.

I would really appreciate if you knew of anyone who you think might be interested that you could discuss it briefly and offer them the option to be contacted with further details about it either by phone or e-mail.

I would be sincerely grateful for any help you could provide in finding the right people for this study!

Participant and Practitioner Information Sheet

Participant Information Sheet

Crafting the Archive:
Creative Responses to Digital Remains
Research Study

Stacey Pitsillides
Goldsmiths
25 St James, Computing, New
Cross, SE14 6NW, UK
Phone: 07972183552
spits009@gold.ac.uk

Principal Investigator: **Stacey Pitsillides - Goldsmiths, University of London**

You are invited to take part in a research study. Before you decide if you want to take part, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and if you wish discuss it with your family, friends or others.
•   Part 1 tells you about the purpose of the study and what will happen to you if you take part.
•   Part 2 gives you more detailed information about the conduct of the study.
Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. I would also be very happy to discuss the study with your friends and family if you wish.

Part 1: Purpose of the Study

What is the purpose of the study?
Previous research studies have indicated that it can be considered a very challenging to inherit a large archive of Digital Data (this might include social networks, e-mail accounts, websites, pictures, writing, music and other digital content) and difficult to understand what to do with it or how to organize it. This study seeks to explore creatively the potential value and memories left online after someone has died. This research will be both practical, using the digital archive to create a memory artefact, and written, contributing to the wider research community. It will also be used to better understand how our lives online affect bereavement and whether creative methods can allow people to form a different relationship with that data, celebrating the person's life online.

Why have I been invited to take part?
You have lost someone close to you within the last five years and have responded to the flyer stating you are interested in participating in this study.

Do I have to take part?
No, it is up to you to decide whether or not to take part. If you do decide to take part, as well as this information sheet and my details to keep, you will be asked to sign a consent form before the interview.

Can I change my mind about taking part?

Yes of course. If you decide to take part you may change your mind at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care you receive from the hospice team, either now or in the future.

What will happen to me if I take part?

If you decide to take part, you will be asked to reflect on the remaining online archive of someone close to you. This might include their social networks, e-mail accounts, websites, pictures, writing, music and other digital content. You will have the opportunity to consider which specific elements are the most representative of that person's life and how you would like to remember their actions online. What would the most fitting tribute be? You will then be partnered with a creative practitioner who will work with you to create a meaningful artefact that holds the key moments from your loved ones digital lives. At the end of this process you will be asked to take part in a 30 - 60 minute interview where you will be asked to reflect on the process and final memory artefact telling me your thoughts, experiences and how you have found the process.

What are the possible benefits of taking part?

This study will provide you with an opportunity to find the reflective space to sort through the online archive and create a memory artefact. This in turn may alleviate some of the stress associated with 'sifting through the digital to find a particular memory'. You will also have the help and support of a creative practitioner who is trained in bereavement. There will be prearranged designated times for meeting with your personal practitioner which will not be longer then 45 minutes for each session. As the process is flexible and involves honest conversations about the deceased there may be other benefits to your own personal bereavement process which we are currently unaware of.

What are the possible disadvantages of taking part?

You may find the process of going through all aspects of the digital archive painful. You are of course free to stop the process at any time if it becomes too intense, however through the support of myself and your personal practitioner we aim to focus the study on positively remembering and celebrating the deceased. Some people may also find the process of collaboration frustrating, however as the process is flexible the particular roles and processes of the participant (you) and practitioner can be renegotiated at any time to find a better arrangement for moving forward.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or possible harm you might suffer will be addressed – the detailed information on this is given in part 2 of this information sheet.

Will my taking part in the study be kept confidential?

Yes – I will follow ethical and legal practice and all information about you will be handled in confidence. The detailed information on this is included in part 2 of this information sheet

This concludes Part 1 of the information sheet.

If this information has interested you and you are considering participation please read the additional information in Part 2 before making a decision about taking part.

Part 2: Detailed Information about the Conduct of the Study

What will happen if I don't want to carry on with the study?
If you do decide to take part you are still free to change your mind at any time and withdraw. You do not have to give a reason.

What if there is a problem?
If you are unhappy about how you feel you have been treated during the course of this study, or how any aspect of it was carried out then please contact: Sarah Russell (details at the end of this form). You can also direct complaints to the Hospice of St Francis Complaints Procedure (Policy No: D113) which is available from Alison Briant Director of Clinical Governance and Nursing at the Hospice of St Francis on 01442 869550.

Will my taking part in the study be kept confidential?
All information collected from you during the course of this study will be kept confidential. Your name and details will only be known to me. The complete recordings will be stored securely and only I will have access to them. Your recorded interview will not be stored or transported in unsecured areas such as the internet, email or other organisations computers. Information that could identify you will be kept separate from the recordings. Digital interview recordings, notes and other related electronic data will be stored on computers that are password protected. All data storage and use will comply with the Data Protection Act (1998) and kept by the Principal Investigator for 7 years, after which all the video recordings and interview transcripts will be destroyed (shredded).

Using your images and words to illustrate the research study findings:
There will be a final exhibition of this research project. Should you wish to give consent your artefact will be exhibited along with a couple of select quotes (or short video sections) from your final interview, this process can also be anonymised for the exhibition. In addition to the exhibition, still or moving images, audio excerpts and quotes will be used to illustrate findings from the research study in my final theses, education lectures, presentations, conferences and journal or book publications. There is a possibility that you may be recognised (where your image and words are used to demonstrate your thoughts). When I present these images and audio excerpts and quotes, I will not reveal your name at any time.

How will the video or audio recorded interview be carried out?
At your interview I will answer any further questions and confirm your consent form. I will then set up the recording equipment and when you are ready to start, turn the equipment on and ask you to tell me your experiences and thoughts about the memory artefact produced, your collaboration with the practitioner and how you now feel about the digital data left online. During the interview I may ask you to clarify or expand on some of your answers as well as jot down some memos and notes – this is to help me to remember all that you have said. The interviews will be videoed or audio recorded so that I can be sure that I remember and understand correctly all what you say. You may watch or request a copy of the video or audio recording and the transcript if you wish to do so. You may withdraw your consent to participate in the video or audio recorded interview at any time.

What will happen to the results of the research study?

When the study ends I will discuss the findings in a workshop of researchers at the Goldsmiths, University of London and the Hospice of St Francis. I will also publish and present my findings in order to help designers, professionals in computing and health professionals to understand better the affect digital data has on bereavement and how better design can affect people personal experiences with digital data after death. At the time of your interview I will ask you if and how you would like a summary of the findings.

Who is organising and funding the study?

The study is academically sponsored by Goldsmiths, University of London and professionally supported by the Hospice of St Francis. The study is self funded and part-supported through use of space and team engagement by the Hospice of St Francis. I have five years experience of considering personal narratives and organizing targeted events to further discussion into what happens to our digital data after we die (please see: www.digitaldeath.eu for further details). I am also an experienced design practitioner, researcher and educator.

Who has reviewed this study?

This study has been approved by the Goldsmiths, University of London's Ethics Committee and the Hospice of St Francis Clinical Governance Committee. This study is being carried out and supervised as part of my Doctorate in Design at the Goldsmiths, University of London.

Contact for further information:

Contact if you would like further information about the study or to participate:

Stacey Pitsillides
Principal Investigator
Crafting the Archive
Goldsmiths, University of London
25 St James, Computing,
New Cross,
SE14 6NW, UK
Research Phone: 07972183552
spits009@gold.ac.uk

Contact if you have any isssues with this study or related to the hospice directly:

Sarah Russell
Director of Education & Research
Crafting the Archive
Hospice of St Francis and
Peace Hospice Care
Spring Garden Lane, Off Shootersway,
Berkhamsted, Herts,
HP4 3GW, UK
sarah.russell@stfrancis.org.uk.
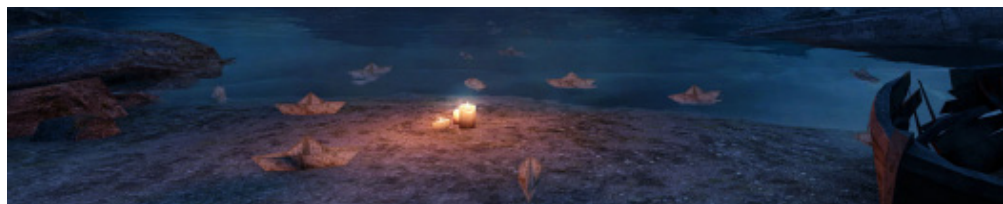
Dan Pinchbeck: Dear Esther

Thank you for reading this information and considering whether to take part. You will be given a copy of this information sheet and a consent form to keep

Clinical supervision: Reflective Writing

02/10/14

Create a deadline with the Hospice in which if the recruitment numbers are not fulfilled three needs to be a recruitment day in which I am available to talk and answer peoples questions about the study.

The view that my PhD sits within a wider narrative of the way that I think and work, post disciplinary/ non – hierarchical/ transparent/ collaborative/ facilitating and engaging

The role of the research in the art therapy community and the novelty there as well which informs this narrative, the relationships that have been built between my team of Art Therapists and their desire to change and develop their community

How will this research be reflected in Art Therapy? Which journal should we target for publication?

How should the research be reflected by the hospice and what would the nature of this publication be?

Not shying away from the complexity of my study but instead understanding what role the complexity plays and how it is strongly with the flexibility of the methodology and the avoidance of a one-size fits all model or of creating a piece of research which needs me as a creative practitioner in order to exist (also the richness complexity gives to the research). This develops a scalable methodology, despite its complexity, which through training and perhaps working with my current team of Art Therapists as ambassadors could develop into a wider research project or professional practice.

How this study works through personal relationships between people and the production of artefacts through and due to these relationships, whether or not making becomes a part of the sessions and the fact that is generally occurs without someone (as a researcher) looking over their shoulders but rather a final reflection which examines and allows the participants and practitioners to reflect and discuss what they have got out of the study and whether it has made them (both groups) reconsider their engagement with the digital.

How this project could apply for different pools of funding, which would redirect the project e.g. from sci/art, aging, digital, health et al funding bodies. The ability this would give to pay practitioners working in the study.

Promoting active rather then passive engagement, prompting the ability to see and reflect on this memory artefact in different parts of the study e.g. with their practitioner in their last session, then in the interview portion of the study and following this within the wider debate of the exhibition particularly if they choose to attend.

In line with this we also discussed having a longer conversation about the study at the recruitment stage (perhaps timetabling at least an hour for this) and explaining, in some depth, the role of exhibition in the study from ground 0 in order that participant is thinking about this as both personal and public from the first session (which is quite a diversion from the classical art therapy approach of confidentiality with some particular Outsider Art exhibitions of works). Also encouraging the art therapists to take a similar approach to the consent forms, as a way of transparently talking to people about what this project entails and what their role is in it.

05/11/14

This week's session reflected more deeply on issues of recruitment and the fact that this is becoming a barrier to the progression of the study, which is causing anxiety.

The main issue is that the study needs to recruit 6 people who have a large digital archive. However the hospice contacts have been reluctant to go for a more direct form of recruitment, such as contacting people directly who may have an interest and have instead suggested trying various other waves of recruitment first.

Flyering: it is hard to tell how this faired as it is unclear how the flyers were distributed or to whom, whether they were announced or just left lying around ect however after a month, when this method of recruitment produced no results. This may also be due to the complexity of the study and therefore the difficulty of explaining this within the space of a flyer.

I had also reached my set deadline and therefore needed to suggest a new tactic. I asked for a consultation with my hospice team to discuss further methods of recruitment. I also asked whether I could come to one of their remembrance events, as I believed the clients would be in a more reflective frame of mind in these sessions and thus more open to considering the benefits of this study. I also believed that my presence would help people to understand the nature of the study and how I believe they could benefit from taking part. I was told that I could not attend the remembrance events/ memorial evenings, as they are very client/ carer led and more focused. It was suggested to me instead that I attend personally one of the coffee morning they hold at the end of each month, as they are open to the

public. Upon arriving for the coffee morning I was then told that the people there may not be the right people for my study as it is generally attended by older people who have lost a partner and thus not typically having a large archive of digital data to explore. This was correct and the coffee morning produced just one viable candidate which has been contacted and that I am waiting for a response from.

The next suggestion was to draft up a very personable letter addressed to St Francis's bereavement councilors asking whether they could possibly discuss the study briefly with clients who they think may have an interest in being involved and ask if they would be happy to be contacted with some more information. I need to be clear about how this is going to work and what the timescale is for this part of the recruitment i.e. how many therapists will have this passed on to them, how many clients on average do they see, how many may fit the remit of this study ect.

In general the advice during the clinical supervision was to be more bold when contacting the hospice and try to see what I am asking of them not so much as a demand (in which my tone is apologetic) but as a part of an opportunity and try to get them to see the study as something which can offer the hospice additional support to their clients, exciting research and publicity through the exhibition. It was also suggested that I consider each time who I am speaking to and try to address the things that will appeal to them in order to get the study moving. It was also suggested that I ask direct questions about how my material is being distributed, who is responsible for it and give clear deadlines. The issue is often that I am trying to be understanding that people are busy and that my study is just an extra thing on their work load, however if I keep being understanding I will be kept in this state of limbo forever.

There is also the issue of the lack of response to e-mails (generally across the past two years) and the fact that perhaps instead of saying no or I'm too busy it is easier to just not reply. It was suggested by my clinical supervisor that this is perhaps due to the demanding environment of the hospice, in which people are always asking a lot of you and as they are very ill or dying it is very difficult to say no, so saying nothing somehow becomes part of these environments. It has been quite enlightening to see how the hospice works as a very different institution to the university. It has its own protocols, anxieties and red tape. The way they want to move systematically through the various stages of recruitment in some way makes sense to them but to an outsider it seems laborious and inefficient compared to direct recruitment which would approach people whom the hospice knows have a strong connection to technology and which they obviously have considered already. One of the reasons is the commitment to the study, they believe that if people

approach the study themselves they will be more committed then if they were offered it. They also felt that by offering it from the hospice they might put pressure on people to do the study. It was suggested that I keep in mind that these struggles are an integral part of the process and that they are helping me to understand more fully the hospice environment.

I also went over a meeting I had recently with my team of art therapists in which various anxieties came to light. One of which being the anxiety of being them viewed as an artist and having to produce work that would be exhibited as part of the project. The idea of putting their own practice on display seemed quite scary for many of the art therapists, perhaps because they believe others would judge their work as art and find it lacking. The action point on this would be to put together an inspiration e-mail containing a range of examples that might get their creative juices flowing and get the excitement to overcome the fear again. Perhaps it is just pre-study nerves.

03/12/14

Following on from last month's session on ways of pushing forward recruitment and being bolder in my use of timelines and goals. In this month's session we started by analyzing, in some depth, the responses I have been receiving from the hospice and the fact that as I try to move forward with the project and recruitment the upper level management have become increasingly defensive, listing in great detail all the ways they have contributed to the project thus far and all the complexities they have encountered. This led to a discussion around the make-up of the hospice itself and concerns around internal politics and the need to be seen to be 'making an effort' interfering with the project itself (with the e-mail itself being targeted towards the rest of the staff at St Francis rather then towards myself).

It was decided that as I seem to be hitting brick walls every time I suggest something to the hospice director that it may be prudent to begin to try and establish other modes of communication within the hospice and develop alternative strategies in line with this. In addition to this rather then cc'ing everyone into the conversation it would be better to write brief, focused e-mail to one person, thus taking the burden of transparency away and hopefully getting a more targeted response.

1.   It was mentioned in the e-mail that they have advertised my project via their Twitter and Facebook accounts. They have 2,237 followers on Twitter so the idea for this would be to develop a social media campaign which would try to find suitable candidates via digital word of mouth, appealing to people in a personal way

and along side this to approach the person who write St Francis's tweets on Twitter itself in order to bypass communicating with the Hospice directly.

2.   Contacting Sam Doherty (an Art Therapist at St Francis Hospice) who is also participating in the project and has been a positive ally in the past to share with her my struggles and ask if she has any positive suggestions of how I could further tackle this.

3.   To contact the Clinical Bereavement Coordinator to ask if it is possible to get the contact details of the bereavement councilors who have been given my recruitment information to discuss with their clients in order to see what the response has been to the study and whether they need any further information.

4.   I have also been in contact with the Voluntary Services Coordinator who has been very helpful and enabled me to get the volunteer discount when applying for DBS within the Hospice. As she is a very approachable and helpful person she could be the right person to widen my network of contacts by sending my recruitment information, as I have previously done with the bereavement councilors to a range of volunteers who may still be in touch with clients who no longer attend bereavement sessions with the hospice but may be ready to reflect on the wider narrative of their loved ones lives. It is important to make clear here the vital role that volunteers play in the running of the hospice and the fact that I am not looking for people who have been recently bereaved.

5.   Contact Kim who spoke with me on a panel at St Francis in May 2013 and was working on a project where she took photographs of her deceased ex-husbands possessions to keep the memory of where they were before dismantling the household. I would like to both update her on the projects progress and ask if there is any advice she could offer or anyone she knew from her connections with the hospice that may be interested in the study.

6.   On the 9th of December follow-up on my previous e-mail to the Hospice Director in regard to setting up an event/ workshop which aims to help people understand what can be done with the online data after death in line with current ways of accessing, making memorial groups, legalities, archiving ect and aims to open up the conversation of how to go beyond this in line with the project, through this I am hoping to have useful conversations with people who would like to further explore this in a creative way within my study. Questions to address: could this piggyback on any other event? Have there been any events of this kind in the past? Making sure the event is clearly targeted towards service users and not training,

therefore making sure it takes place at the right time of day, day of week, room ect.

05/03/15

There has been an extended break between my previous clinical supervision session and this one. The beginning of the session was dedicated to an update on the way that the methods discussed in the session before Christmas had progressed the recruitment.

There has been very little movement on recruitment I have reached the point where I need to have a deadline for this process and begin to consider alternative ways of writing up my thesis and the experiences I have had with the Hospice over the past four years.

The deadline for progression with the hospice has been set to just after the 10th March in which I will go and present my work to a mixed group of bereavement councilors and volunteers at St Francis. I will try to present my work in a compelling way that is very geared towards personal engagement i.e. 'gran's thimble collection' and does not mention titles e.g. PhD. I will try and use the session to acknowledge the fears people might have about participation e.g. creativity, what they might find et al. I will also make sure to discuss the work in way that shows the approach is flexible and they will have the freedom to develop the process as they move through it in a personal way. I may also try to do an activity with them like asking them to close their eyes and think of a memory that is not too personal but makes them smile and then consider what form it takes and how you would go about saving or sharing that memory (making sure that people do not go too deep is important). Also keeping track of the people Freda is contacting and to ask her if there is a point where they would like to talk to me.

Some of the advice in this session also conflicts with my previous session with my PhD supervisor. Firstly my clinical supervisor was worried that by opening my talk discussing Freda as an example I might alienate some people that can think, well I am not like Freda, so I cannot participate. Another difference in opinion was that my clinical supervisor strongly felt that to get involved with recruitment at Goldsmiths would be another long and arduous process and that this may not provide any further solutions for my current dilemmas.

We discussed the fact that it is more a feeling of not wanting to give up my current idea and do something 'less' with only one study and also not to feel like I have let people down. These are two separate issues but they link together. There is a general disappointment with the progression of the PhD and the challenging nature

of what I am trying to do. I have not moved forward a lot but I have learnt a lot about being a researcher and in this way through having intense collaborations and discussion channels with people have uncovered a lot of new knowledge and groundwork that will help both myself in the future and other researcher looking to challenge this difficult topic. This research is already pushing this area forward and having one strong case study will help to ground the methodologies in place and test how this could be expanded in future. My team of art therapists could also be taken forward on to apply for a funded project in future to explore this area further within different institutions or other avenues. I should appeal to their creativity and ask them if there is something they would like to do further together if what I previously set out is not possible.

It is a real wrench to think about writing up my PhD without having achieved the goals I set out for myself and without having the outcome I have envisioned in my mind so many times but this is something I am trying to come to terms with and consider the richness of the narratives I have heard from so many different people which gives me a strong breadth over this topic and an ability to add to current research in a practical and future-facing way, to critique some of the current situations in the hospice environment and to hopefully see the work I have done there not as a waste of time but something that can be discussed in an open way throughout my thesis.
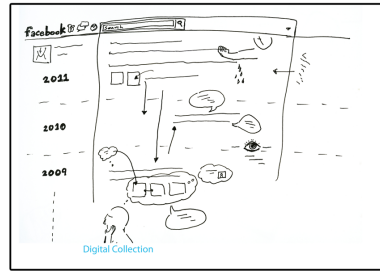
02/06/15

There are no reflections on this session as it acted as a conclusion to the clinical supervision. It focused on updating my clinical supervisor on progress, that I had managed to recruit three participants and tying up any loose ends from previous sessions.

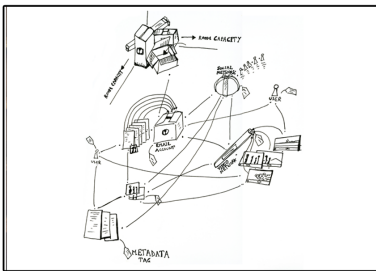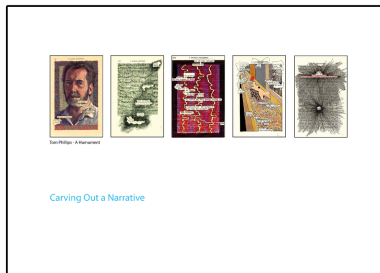**Presentation for Bereavement Volunteers Training Evening**

1

2

3

4

5

6
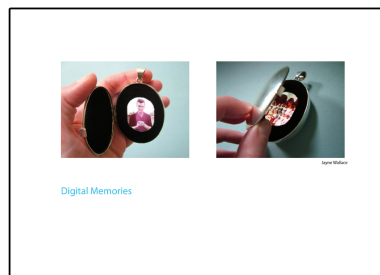

7
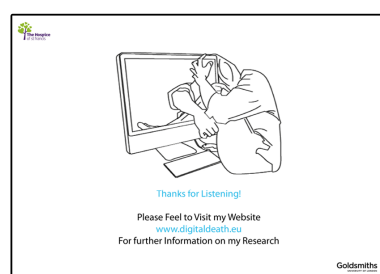

8

9
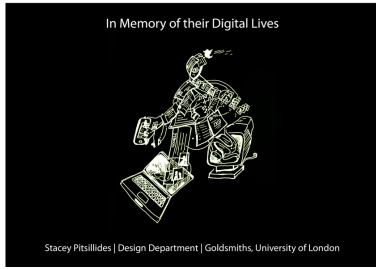
10

APPENDIX 3: COLLABORATING WITH SAM

Sam was situated at the Hospice of St Francis right from the beginning of my research, as an art therapist and children's support worker. I remember we had one of our first conversations about digital spatiality and her understanding of her clients' approach to tangibility and making, after a consultation meeting at the hospice on the 23rd June 2014. Sam, who had lost her good friend Charley some years ago, wrote to me in retrospect asking about being a practitioner within my research but really wanted to be a participant. When the opportunity arose for support care staff and volunteers at the Hospice of St Francis to become participants within the research, she moved across the boundary from practitioner to participant. This gives her the opportunity to reflect on the research from both sides and to explore her own practice and prior encounters with grief.

The sessions gave me the opportunity to get to know Charley, who was a significant player in Sam's life and development from teenager to adulthood.

> "Sam had known Charley when they had both attended a school for girls and hated it; they were both mischievous characters and gelled with each other almost immediately… she was a true friend from the start even asking to move her room closer to Sam to make her feel welcome. Then came the insider jokes and group connectors, such as going out down a treacherous alley to smoke and constantly stepping in 'badger poo' until this became a 'thing' or seeing a mushroom and becoming incredibly excited, shrilly 'OMG its Nature'."

(Extract from field notes with Sam, 4th August 2015)

Sam's reflections on Charley are also reflections on her own youth, intermingled with her guilt of not having kept in contact. The liveliness of the description shows the qualities of their friendship and their playful engagement with nature that formed such a strong part of their school experience. The mushroom and badger mentioned are entwined in this experience and her understanding of Charley, despite who Charley may have become later in life, for Sam they will always remain as her things, including pictures of her with a mushroom on her shoulder or the fact that she always had a mushroom birthday cake. Her admission that they have known each other longer in death than in life shows that this bereavement is as much for the absence of contact as it is for the person them-self. Charley will always be a mischievous teenager to Sam, and the artefact will have to incorporate this. When asked to reflect on the digital archive there is also a discussion of absence.

"'There are no photos of us together on Facebook' due to the timing of their friendship but Sam used it [Facebook] all the same to ask people to wear colour at the funeral as this was how she imagined Charley would have wanted it. She describes Facebook as a good bookend for their relationship… They were not together there but this [is] one of the strongest triggers to remember and a place to put all these feelings, allowing for this internal process."

(Extract from field notes with Sam, 4th August 2015)

Sam's self-observed instances of grief online also give glimpses into her participation in this research. She claims it is a way of inscribing her Charley onto another reflective surface and exploring how she is able to confirm her life.

I believe that talking about Charley and exploring her life with me was another way for Sam to inscribe her relationship. In my absence, she used her iPad particularly as a tool for quick reflection, as it could be easily accessed in between her own art therapy clients and could capture thoughts and feelings in the moment. She also used the iPad to rework old photographs of Charley, transforming them into colourful absences. Over a period of negotiation and conceptual development, which closely followed Freda's approach Sam chose to work with mushrooms. Sam's mushrooms are made out of felt; it is not a material she has used before. In fact, she states that she would never conciously choose to use it as it reminds her of craft fairs and she is usually a painter, but she enjoys the repetitive process of poking the tiny needle in hundreds of insertions that make the soft and loose strands submit and solidify into a hard mushroom-like structure. She parallels this to her experience of the memory of Charley, that through stabs of repetition over the years the memory becomes solidified and that as she spends more time getting to know Charley in death then she did in life, these memories gain a solid form which constitutes their relationship. She also chooses to make the mushrooms colourful to mimic her desire for people to wear colour at Charley's funeral. It also plays with ideas of authenticity, as these mushrooms do not aim to be mistaken for real mushrooms. It is through this commitment to authenticity that the smell of the forest was discussed but finally rejected from Sam's work. As a multi-layered and complex environment, we felt there was no way for us to truly capture the forest and the only ways we could think to manufacture it felt too artificial. The notes of the forest cannot be easily produced and the home is ill equipped to become an olfactory lab. However, we did wish to incorporate some multisensory elements. Therefore, sound was returned to through the Dictaphone that Sam and her friend Charley used to carry around and capture their young voices. Leaving messages. It

seems appropriate that these messages should be added to and grown into the installation.

It is during our discussion of the Dictaphone though, when Sam really begins to question how the digital engages in this experience of Charley:

> "A Dictaphone containing three seventeen year old voices, the voices are chanting, singing and shouting their nicknames and in jokes. The recording has been made for simple fun and pleasure. A pleasure in itself to playback and giggle, years later this capturing of times is far more. It questions the public vs private, the MySpace and Facebook accounts that were created, contain and collect messages but the recording remains in a drawer and leads to questions.
>
> Should we expose this private thing? How does it come to surface?"
>
> (Extract from field notes with Sam, 10th October 2015)

The felt mushrooms are only the tangible signifier of the archive that also contains sounds e.g. the Dictaphone, mentioned above, in which Charley used to leave messages. Sam describes how she wanted to incorporate these sounds into the piece as they echo the past. The sound aspect is also cumulative, as new elements that did not exist in the archive are able to be added to it as triggers of memory, a major one being a lorry driving by, a lorry company with her surname on it. Every time one of these lorries trundles, Sam has been attempting to capture the sound of it to include in the piece. We discussed how the sound installation, housed in felt mushrooms, could be spatialised across the exhibition to reflect the rhizomatic nature of mushrooms. As an art therapist, Sam has also been exploring how the experience of working collaboratively with a creative practitioner has become a springboard into translating her expressions of Charley into art, while also trying to maintain the feeling and memories.

APPENDIX 4: ANNE AND ELWIN'S COLLABORATION

This section is produced from a collection of e-mails, phone calls and physical discussions with Anne and Elwin over the course of their collaboration. One of the first e-mail updates I received is documented below. However, it should be noted that at the beginning of the collaboration we preferred to have short phone conversations after each session. This was also part of the ethical procedure put in place to make sure that the practitioners were comfortable with the people's homes as a working environment and that they were able to work with the person they had been partnered with. Following on from the first few sessions, we moved our communication primarily to e-mail:

> "I see Anne about every two week, as she found monthly intervals a bit too long. At the moment I have been photographing her work and sending it back to her via e-mail. This is proving to be very interesting in itself, as it is now becoming clear that they are some artworks that works better in digital form and others that will work better in a concrete art space."

> (Extract from e-mail with Elwin, 18th December 2015)

This extract shows the developing collaboration and how Elwin is both supporting Anne creatively but also using technology as a reflection point. The camera is able to frame Anne's work through digital photography and to show a range of details. Anne is also able to evaluate her work in this medium and understand which works need a physical presence; this may have been what drew her more to textual exploration. Through this practice of photographing Anne's work Elwin is also able to show his engagement and care of the work through documentation:

> "At the moment, it's really about Anne honing down concepts and focusing her vision on an actual end production. That, more than likely will involve Anne actually visiting the gallery at some point, so that she is able to visualize her work in situ, this will help to clarify and direct the possibilities of what she exhibit in the actual space."

> (Extract from e-mail with Elwin, 23rd February 2016)

> "I'm very please with her progress on the project - from a very confused beginning where she had no expectations of her own abilities, I can honestly say she is embracing the project whole heartedly and looking forward to the exhibition."

> (Extract from e-mail with Elwin, 3rd March 2016)

These e-mails showed how the collaboration had progressed within the first four months and how both practitioner and participant are beginning to understand the nature of their collaboration. It also shows that from quite an early stage, they are embedding the exhibition into the process of making and conceptual development (as stated within the ethical framework of the project, see Chapter 3, p.82). Following on from this development I also visited Anne and Elwin to discuss the project and see how the work was developing on the 20th April 2016. It was exciting to see the breadth and depth of works within the portfolio. As a designer, I saw the works very much as a collection of small elements that could be placed within a grid or positioned in three-dimensional space within a gallery to make a singular piece, whereas as a painter Elwin saw them very much as individual pieces and was excited by the idea of Anne scaling them up as a collection of independent works. Following on from the meeting it was clear that our discussion had sparked something and Elwin sent me the e-mail below.

> "There is a profile of the artist Brian Clarke on BBC 4 called 'Colouring light'… his amazing use of colour submerges (Matisse like) 'horror' of what he's communicating, his works are littered with symbols of death. However, untainted local colour, which comes straight from the stain glass he uses, makes them quite celebratory of life and living… in the last 15mins of the profile, he make a large and dramatic piece, stripped of bright vibrant hues as a memorial to the passing of his mother. It's quite beautiful and yet has the earthy and gritty northernness of his mother. It is interesting that as his mother has already passed (reminds me of Anne use of black/white pieces), he sticks to the traditional representation of a dark colour and lead to convey the death of his mother."

(Extract from e-mail with Elwin, 24th April 2016)

Here, Elwin is approaching the collaboration as an artist, where he develops a deeper understanding and appreciation of Anne's works by identifying links and contextualising it in relation to other artists' use of materials and approaches. His understanding for the materiality and connotations of stained glass shows how this collection of glass may be seen both in parts, including the process of making it from 'local colour' and in its overall impact. In this way he is also able to integrate the comments from my visit back into the process.

Figure 23: Jeremy Sutcliffe (2007). Oldham's "The Spindles" shopping centre features a stained glass window by Brian Clarke, designed to celebrate the music of Sir William Walton. Licence: https://creativecommons.org/licenses/by-sa/2.0/deed.en

"Clarke's approach to an aesthetic is very linear and analytical in the first instance, it's like poetry, you have to be able to read the 'symbols' together. So, when I watched the programme I kept thinking of how you instantly saw Anne's pieces from the perspective of a designer - which suggested that they work as a 'collective', a collection of signs, systems and patterns having a dialogue with each other. I sort of responded to them, very much as individuals, each individual piece functioning as an emotional whole in its own right. It was really great to see your perspective of the work, it is so interesting and healthy to see how other artists approach art."

(Extract from e-mail with Elwin, 24th April 2016)

This unification of perspectives allows us to negotiate the collaboration as a trio in some instances, where I am able to provide an external eye to the process and consider how it shifts both the focus of the works but also my own understanding of the research I have initiated. During this collaboration, Anne has grown throughout (Ch.5, p.128) as has her body of works, which could be categorised as a collection of textures, materials and development. She is now at the stage where she is beginning to include the archive and it is becoming more challenging as it implies an opening up, an acceptance of sharing that which is most intimate.

205

Figure 24: Anne Marshall (2016). A selection of works from Anne's portfolio which I laid down on the kitchen floor to see the impact they make as a collection and look at how the positioning of specific pieces impacts the collection as a whole.

On the 5th May 2016 she states as part of a mid-way reflection:

"I am aware that there have been a few moments when I have realized that something has somehow 'moved' or 'changed'. I am a very cerebral person and words are important to me so this process has accessed something different and deeper… It has reminded me that I enjoy the creative process. Tim was extremely creative in many areas of his life so participating has enabled me to think about those aspects & to 'draw near to him'."

This paragraph encapsulates Anne's own understanding of how the process has impacted her and shifted her relationship with Tim. She states that by considering what to make and how to work with materials, she has been given time and space to think about the meaning of her husband, considering the things that were important to him and enriched his life, which through the creative translation are now very present in her own life.

In Elwin's mid-way reflection on the 10th May 2016 he also engages with this core objective of the research by acknowledging the material exploration.

"[It is my belief] that for Anne, the development of the physicality of the mediums she is using, has given her physical outlet and a way to tell her story without being too explicit with the narrative. The textural aspect of the artworks conveys a real presence of Anne's experiences as a 'felt' process… to my mind, the digital aspect should give one a sense of the departed presence – in the spirit of the machine, sort of feeling"

Anne's husband was a musician who composed and recorded digital music. Throughout the process we have considered in a range of ways how she may

206

incorporate this into her practice. A sonic element could be embedded somewhere in the piece, perhaps as a hidden downloadable interaction or played from speakers in very specific locations in a very subtle way. However, due to the emotions connected to this music, it has always been a challenge for Anne to access them. In the intermediate time she has been working with The Lark Ascending, a musical score favoured by her husband, and poetry, particularly those that were spoken at his funeral as well as images of him. The most recent e-mail I received from Elwin 10 months after his first e-mail update shows that the collaboration has surpassed words and he no longer needs to describe Anne's progress. She is able to communicate through her work. They also show how Elwin's role in the collaboration has shifted and his passion for Anne's artistic practice.

> "I felt that you may find the last pieces from her creative process of some interest. I remain mute, as they speak for themselves.
>
> The tryptic = sublime!"
>
> (Extract from e-mail with Elwin, 8th September 2016)

Figure 25: Anne Marshall (2016). A collection of recent works that use printed images of Tim in black and white, which are distressed with the signature textured paint effects that Anne has been developing in her collaboration with Elwin.

APPENDIX 5: INTERVIEW TRANSCRIPTION AND CONSENT

Note: the four practice films using the interviews can be found in the USB pocket.
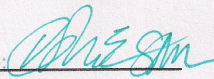
Signed Consent Forms

Goldsmiths
UNIVERSITY OF LONDON

The Hospice of st francis

Stacey Pitsillides
Principal Investigator
Goldsmiths,
25 St James, Computing,
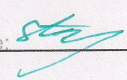New Cross, SE14 6NW
07972183552
spits009@gold.ac.uk

Video and Audio Consent Form
Research Study: Digital Death: The Materiality of
Co-crafted Legacies
Principal Investigator: Stacey Pitsillides, Goldsmiths,
Approval from Ethics Committee at Goldsmiths, University of
London and The Hospice of St Francis, Research Governance.

Please initial the boxes and sign at the bottom

1. I understand that I will be asked to talk about my thoughts and experiences and that the interview will be video and audio recorded. [✓]

2. I understand that the visual and audio recording of my interview will be studied & analysed by Stacey Pitsillides for use in her PhD thesis research. [✓]

3. I understand that my visual still & moving images and audio recording & quotes will be used by Stacey Pitsillides to present the research findings in academic publications, education conferences, design exhibitions or in sessions to interested health professionals. [✓]

4. I understand that these images and quotes may be recognised by those that I know. [✓]

5. I provide permission for full quotes or extracts of my responses to be published within journals or presented within academic conferences with my first name. [✓]

6. I provide permission for full quotes or extracts of recording to be used within the design exhibtion. [✓]

7. I would like my loved one to be anonymized in all reference to this project. [✗]

8. I would like my loved one to be refered to using thier first name in all reference to this project. [✓]

Name of Participant: *Freda Earl* Date: 24.08.2016 Signature: *Freda Earl*

Name of Principle Investigator: *Stacey Pitsillides* Date: 24/08/2016 Signature: *SP*

Stacey Pitsillides: Principle Investigator (Crafting the Archive) Goldsmiths, University of London
25 St James, Computing, New Cross, SE14 6NW Phone: 07972183552 spits009@gold.ac.uk

The Hospice
of st francis

Stacey Pitsillides
Principal Investigator
Goldsmiths,
25 St James, Computing,
New Cross, SE14 6NW
07972183552
spits009@gold.ac.uk

Video and Audio Consent Form
Research Study: Digital Death: The Materiality of
Co-crafted Legacies
Principal Investigator: Stacey Pitsillides, Goldsmiths,
Approval from Ethics Committee at Goldsmiths, University of
London and The Hospice of St Francis, Research Governance.

Please initial the boxes and sign at the bottom

1. I understand that I will be asked to talk about my thoughts and experiences and that the interview will be video and audio recorded. ✓

2. I understand that the visual and audio recording of my interview will be studied & analysed by Stacey Pitsillides for use in her PhD thesis research. ✓

3. I understand that my visual still & moving images and audio recording & quotes will be used by Stacey Pitsillides to present the research findings in academic publications, education conferences, design exhibitions or in sessions to interested health professionals. ✓

4. I understand that these images and quotes may be recognised by those that I know. ✓

5. I provide permission for full quotes or extracts of my responses to be published within journals or presented within academic conferences with my first name. ✓

6. I provide permission for full quotes or extracts of recording to be used within the design exhibtion. ✓

7. I would like my loved one to be anonymized in all reference to this project. ☐

8. I would like my loved one to be refered to using thier first name in all reference to this project. ☐

Name of Participant: *E Harewood* Date: *24-8-16* Signature: *E Harewood*
Name of Principle Investigator: *Stacey Pitsillides* Date: *24/08/16* Signature:

Stacey Pitsillides: Principle Investigator (Crafting the Archive) Goldsmiths, University of London
25 St James, Computing, New Cross, SE14 6NW Phone: 07972183552 spits009@gold.ac.uk

Goldsmiths
UNIVERSITY OF LONDON

Video and Audio Consent Form
Research Study: Digital Death: The Materiality of
Co-crafted Legacies
Principal Investigator: Stacey Pitsillides, Goldsmiths,
Approval from Ethics Committee at Goldsmiths, University of
London and The Hospice of St Francis, Research Governance.

Stacey Pitsillides
Principal Investigator
Goldsmiths,
25 St James, Computing,
New Cross, SE14 6NW
07972183552
spits009@gold.ac.uk

Please initial the boxes and sign at the bottom

1. I understand that I will be asked to talk about my thoughts and experiences and that the interview will be video and audio recorded. ✓

2. I understand that the visual and audio recording of my interview will be studied & analysed by Stacey Pitsillides for use in her PhD thesis research. ✓

3. I understand that my visual still & moving images and audio recording & quotes will be used by Stacey Pitsillides to present the research findings in academic publications, education conferences, design exhibitions or in sessions to interested health professionals. ✓

4. I understand that these images and quotes may be recognised by those that I know. ✓

5. I provide permission for full quotes or extracts of my responses to be published within journals or presented within academic conferences with my first name. ✓

6. I provide permission for full quotes or extracts of recording to be used within the design exhibtion. ✓

7. I would like my loved one to be anonymized in all reference to this project. ☐

8. I would like my loved one to be refered to using thier first name in all reference to this project. ✓

Name of participant: ANNE MARSHALL Date: 24.8.16 Signature: A. Marshall

Name of Principle Investigator: Stacey Pitsillides Date: 24/8/16 Signature:

Stacey Pitsillides: Principle Investigator (Crafting the Archive) Goldsmiths, University of London
25 St James, Computing, New Cross, SE14 6NW Phone: 07972183552 spits009@gold.ac.uk

Scanned Interview Transcription

This section contains the final interview questions and transcripts of raw footage that I have worked with, as part of the analysis of collaboration, aesthetics and curation in Chapter 5. The prompts, under the questions below, have been used as concepts that I have traced across all the interviews.

Final Interview Questions

These questions have been constructed to help you reflect on the process, artifacts and exhibition to consider how you can describe the depth of your experience. They are a gathering of the living practices that have been at the heart of our working together for the past year or so. As they aim to gather what has been building at the surface, I would like you try and keep your answers quite brief, around 3 – 4 minutes each.

— Introduce yourself (and the person you have lost) briefly?

1. To begin with please briefly describe your experience of being involved in this process?

   Prompts: expectations, meaning, changes over time, challenges, nature of collaboration, stories, confidence, ownership, personal growth et al.

2. How would you describe the artifacts you are producing (that are being produced)?

   Prompts: role of things from the archive, making, aesthetics, inspirations, meaning, skill, physicality, digitality, embodying the person, editing, labels (art/design/craft/other) et al.

3. How does the knowledge of the upcoming exhibition evolve or augment the artifacts and process?

   Prompts: private/public, sharing, family, re-framing, ending, display, labels (artist/participant/maker/interpreter) et al, personal conflicts, vulnerability, meaning.

Quotes from filming

Freda

Multiple system atrophy trust

"I have been looked after by the hospice ever since Victor died two years ago and after 1
that someone came round and said there's this interesting project going on would you 2
like to be part of it and I didn't have the least idea what to expect, I didn't have the least 3
idea how I would get on with it but I always say yes, so I did and as time has gone on I 4
have understood what it is about and I find myself explaining it to other people"

"I have described it in the form of Uncle Fred made a stool that is his physical heritage, 5
if it's a beautiful stool it becomes part of the family treasure, if its no good it ends up in 6
the cow shed but its still useful because they keep their chicken feed on top of it, that is 7
his heritage, it is always there"

Project Describe → from participant perspective

"When people's heritage is digital on computers or anything like that, it only lasts as 8
long as the computer and therefore this seems to me a very good way of converting that 9
sort of thing into something comfy that you can actually look at and say this explains 10
what Victor was about"

"I was very amazed at the beginning, how short it was a time before I felt that you who 11
had never met Victor actually knew him as well as I did and I felt this was extremely 12
valuable for me, it gave me a great deal of pleasure that, that was happening and I think 13
it made it easier for the whole project to move on"

"well in one sense its very ironic because Victor actually didn't really like the digital 14
age at all. I never persuaded him to use my digital camera which he said was far too 15
difficult, although he used to do the most amazing things with one that he set for 16
himself, which I found far too difficult"

"It was very interesting to find a way of transferring what he did and what he said and 17
what he was into something that 18

"Because he was a person who had no love for digital things, a bit of luddite over things 19
like that, he used computers when he was working at the economist, that was when he 20
had to use it and when both of us were working in the town council we both had to do 21
this a great deal but in one sense it distinctly ironical to have a digital heritage for 22
Victor and to transfer the things that he was interested in and the things that he has done 23
into that sort of from has been an interesting exercise"

out?

"well it started I think with his funeral, we had a humanist ceremony and so it was 24
created by us with the help of the practitioner man who did it and we came to the 25
conclusion that there was a theme that Victor was a great lover of cats, got nothing to do 26
with being digital, apart from the photographs and cats have nine lives and so had 27
Victor. He narrowly missed being on the Empress of Venaris, which was the refugee 28
ship, the evacuee ship that go sunk in the Atlantic, he was nearly on that, we nearly got 29
run over on a number of occasions, he nearly got into train accidents on a number of 30
occasions and then the trains started to come and I realized that this was actually a great 31
theme that ran through his life."

1

"starting with being a proper engine number collector who used to go all over London 32 wearing, not an anorak because they weren't invented then but he would have done if it 33 had been but his main interest was the economics of them and how they worked and 34 how they took part in the economy."

"simply by going through the times and the ways in which trains were important for 35 him. When he was a very small boy during the war they used to play cricket, all the 36 local lads played cricket on the field where North Park Hospital is now and one lad was 37 on the bridge and there were of course steam trains and when a train was coming the 38 shout went up, the cricket balls went down and they all pounded up the bridge to take a 39 look at these and they all had their different reasons. Victor's reason was that he was so 40 interested that with the limited amount of rolling stock available, that half of it had got 41 bombed on the railway and the railway lines had got bombed that the most 42 extraordinary selection of trains was coming underneath that bridge and that really 43 implanted in him a love of them and an interest in them"

"I didn't meet him until we were in our early 20s so I have nothing to do with any of this 44 but if you live with somebody that long and there's something that's important to them, 45 I can almost believe that I was there and in that sense it means a lot to me, yes" 46

- gran and her thimbles
- Dear Esther

"I think it's the story more then anything else, the story that's been created in clay" 47

"so if anybody can actually look at it, its not too difficult to know what's going on" 48

"Most of the family couldn't understand why he was so mad as to be interested in trains, 49 its very lucky that he married a wife who was more then happy to go and join him and 50 find out, so in that point of view it is actually in a sense quite a private thing, its 51 something that we really did enjoy doing together"

"In later years we did a lot of train travel, over Europe and this country as well and that 52 was in one sense a private thing and it also connects with the man who ran the 53 allotments who was equally passionate about trains and that provided another bond, 54 another link and so when Victor was ill, he was willing and able to help because he was 55 another train man."

"Everything comes to an end. They talk about when anybody's had a bereavement, 56 when something has happened and you haven't been able to come to an end you feel 57 that you've been deprived. You must work through what there is to find out about, what 58 there is to remember, what there is to learn and then you go and say right that's fine, I 59 understand that its finished. Then from the exhibition point of view, that will be that. I 60 will also be interested to hear what other people think of it."

"yes I will be very intrigued to know how they would react. I think possibly they would 61 look and say what is this about. Some of them are going to say 'oh look, its about trains, 62 what's that got to do with anybody' and then if they are looking at it in the right order 63 which I hope by the way its made they can do they will actually pick up on the story 64 and see what has happened"

2

"It will exist. I have a horrible liking for things that I have made. I am very happy to 65
have them around and they tend to end up in the garden. So from time to time I think 66
hmm when the rain gets on that and the frost gets in, that's going to fall off." 67

"This frame of mind that I am in now and the frame of mind that I was in when I first 68
started it is very different so the making it has been part of that process and I think its 69
been a very helpful part of that process. I mean I have now recreated for myself a life 70
with a lot of new and interesting things in it and this has been one of them" 71

Anne

"My name is Anne and I became part of this project because I was working with 72
somebody from out of the hospice, well my husband didn't actually die there but he was 73
there when he was ill and this is all about him really. His name is Tim, he was an 74
Anglican vicar. He was a very creative, interesting man. He did a lot of photography, 75
music and all sorts of things like that, very wordy as well."

"When I started this all originally my idea about it was to think about him and what he 76
meant to me and there's all these words and music so I have been struggling a lot trying 77
to incorporate words into this, hasn't really worked very well." 78

"So its about him and it is about my journey through this time of grief really and its 78
interesting coming to this bit now. Looking back I can see the work that I've produced 79
actually has reflected to some extent this journey. It started off very dark and I dunno, 80
quite slashy. I was etching things, scratches and cuts and things like that and now I've 81
come to a place where my daughter actually said to me a couple of weeks ago, she said, 82
its much lighter now isn't it."

"Although there have been occasions where I have been in the process of making, I 83
have actually experienced something that's very different, I am a very thinky wordy 84
person and its been a very different sort of process which is still continuing" 85

"Right at the very beginning, I was very anxious about doing it. I thought I needed to be 86
an artist of some sort and I needed to have technique. I didn't know what I was going to 87
do, what it meant and how I was going to fit it into the brief that was the title of your 88
project to start with. So its been challenging personally because I don't talk about how I 89
feel very easily and it felt very exposing to actually have to produce something that 90
somebody was actually going to look at, because I though it was all rubbish, you know. 91
I hadn't done anything like this before, so it was personally very challenging in that 92
sense."

"But having Elwin to work with has been fantastic, he's a real inspiration and 93
encourager actually and he's held my hand all the way through but without being 94
intrusive at all."

- deep appreciation and mutual respect (Rothko/ value)

"I did some years and years ago, I did some ceramics and I haven't done anything for 95
nearly 40 years. I think its been interesting to come back to that and I've always felt that 96
Tim, my husband was the creative one and I just wouldn't have done anything like this 97
and its such a different thing to do, to work with your hands and produce something just 98

3

for yourself. So im really delighted to do it from that point of view and im not quite sure 99
how it fitted into the remit, it took on a life of its own really"

"There is a sense all the way through, I sense that I think of musicality about it which I 100
think. Tim was a musician and I'm defiantly not but there is something of that, that I 101
think has been there."

"well I've never used any of the materials actually and Elwin introduced me to them. 102
When I did do some creative work, it was 3D, it was ceramics but what ive done, I think 103
is work with texture and organic things I suppose really but I keep going back to word 104
actually, there is a particular poem which was written by somebody called Prudentius 105
in, I don't know about 300 AD or something, which I don't know, seems to be a kind of 106
backdrop to it really and the first line of it is: *"Take him earth for cherishing, to thy* 107
tender breast receive him. Body of a man I bring thee, noble even in its ruin." And I 108
think there is a lot of this that is about earth and nature stuff and it is a very profound 109
thing to stand by a grave and have that read, which it was at Tim's funeral.

"It has been a dark time in lots of ways and I think doing this creative work has allowed 110
me to be in touch with feelings, that are more difficult to be in touch with if your just 111
thinking and talking. And actually its quite therapeutic the physical doing of it and its 112
very – very, I do it with my fingers literally, I rub the things and whatever so actually 113
physically being involved in doing something as well as has been quite helpful" 114

proficiency in materials:

"I think at the beginning it was just getting to grips with using the materials, whereas 115
now I'm thinking more about the effects I'm trying to create and how I can do it and I 116
think, I dunno I just like the materials actually because in the past I would have gone 117
maybe more for photography and things like that, the actual physical process and its 118
really really helpful."

Labels:

"well this particular series of things I suppose is a story isn't it, it's a kind of part of the 119
story of traveling through grief, I suppose. I mean that's what's at the heart of it. It was 120
very much about the feelings at the beginning, they were really kind of difficult, dark 121
feelings, it wasn't possible to express very easily. Whereas now I feel, it's interesting 122
because it is all lighter that somehow."

"I've traveled with the art work through some of those dark things and it does reflect to 123
some degree where I am and how I feel now" – parallel journey of the works

"I think grief is a thing that it doesn't change, it doesn't mean that the thing that's 124
happened always happens but I think it's possible to view it differently over time. I 125
think its interesting because even the lighter things now, there's always bits of it that are 126
very dark and I think there's this idea of sort of travelling through things. I think there's 127
a lot of kind of movement in the pictures. At the beginning they were much more solid 128
and static, I suppose. Whereas now it feels more fluid, it feels more, I feel like I want to 129
have music over it or if I could do musical notation I would be doing that. If I had 130
beautiful handwriting I would be writing."

Exhibition:

4

"I don't think it does, I think it makes me feel things, like it feels quite scary and quite 131
exposing I suppose but I think at the beginning it felt like a more difficult thing then it 132
does now. I think, you know because I've got nowhere to keep this stuff, when people 133
come into the house, they see it. So I've had to begin to talk about it a bit and obviously 134
people who are polite and things, you know positive feedback helps so having had that 135
it doesn't feel quite so difficult"

"I don't think the exhibition in itself changes anything about it I think it is some kind of 136
ending though and that this is actually a very defined period of work really."

"You know the theme is a common theme to all these things and you know Tim and his 137
death and his life and what he meant to me is at the heart of this, so in that sense its got 138
to be giving me a little hand I suppose the exhibition feels like the end which I don't 139
think I've really got to grips with."

"It will be interesting to see it in relation to other peoples work as well" 140

"well I still feel I'm in the middle of it. I'm still in the process and I suppose I'll only 141
know how I feel about it when I get there but its interesting to have a date and say 142
actually this fits in between the date we stated and the exhibition which is the actual 143
ending"

"Its interesting just looking at the folder of stuff I did there and I feel a lot less 144
comfortable about having the early stuff then this. This doesn't feel as intense I suppose. 145
Its difficult isn't it as they [the family] didn't have me down as someone who did this 146
kind of stuff."

"I had a very interesting experience about a week, two weeks ago, a fried of my son's 147
was here and his dad came to pick him up and these were under the stairs actually and 148
he said something about what's that and I said oh its something I was doing as part of 149
this project and he just looked at me and said I didn't have you down as, I think he said 150
painter actually… and I said its interesting as a lot of people have been really surprised 151
and its interesting how we think we know people, people we've known a very long 152
time, so its quite nice to surprise people. I think my children have been very surprised 153
actually and I don't know what they think about it. I haven't had any real comments 154
about it yet"

"I have to say this though one of my concerns all the way through has been that I have 155
done this and it is my process but actually this is Stacey's project, its her PhD and its 156
actually very important, its part of that. Am I doing what I am supposed to be doing, 157
which was part of the difficulty at the beginning but actually there wasn't really a remit 158
and I've been able, I don't know how other people have felt but the way you have 159
managed it/ run it or whatever the terminology is has enabled it to be yes, your project 160
but actually has enabled it to be my project too and I think that's what's enabled me to 161
do what I have done."

"I think the fact that you've enabled me to do that has been really fantastic, so thank 162
you"

- important to have imposed a process on someone (ethics and integrity)

5

"It was interesting the time we had at the gallery because obviously that was the first 163
time that Freda, Sam and I had met and to understand what we were all doing and I was 164
quite interested in myself 'I wonder how these are going to work together, how were 165
going to do that and I suppose it might have been, I dunno, it would have been different. 166
It would have been interesting to know how it would have affected things if we had 167
done it as a group, I mean I am glad that we didn't personally but it is interesting 168
because what you see, everybody's grief is different but in the same sense we have a 169
common theme and its just so interesting to see just how completely different people's 170
work is and just the materials even, they couldn't really be much further apart" 171

Me "but there are some themes and there are some commonalities, there's an interest in 172
authenticity, there's an interest in captivity, there's an interest in the process of making 173
and the action of making and the feeling of what it means to put brush to page or push 174
the needle in and out of the felt or make with the clay"

"we were just talking this morning about size and how the size of what you work on can 175
actually change how you work and for me its actually taken the skin off my fingers 176
doing things like that but actually that physical process… working through these 177
emotions as well … it feels like a physical process of taking it from inside to outside but 178
actually for me there's nothing much between me and the work, there isn't a brush, 179
maybe there's a piece of charcoal but mainly its really direct. I think that probably 180
really helpful."

Elwin

"I'm Elwin, I'm a fine artist and an art therapist and I was asked to the project … 181
because I'd actually done a lot of work in palliative care and I also lost my mum to 182
cancer you know, so that was quite important and that was very important for me to… 183
you know work from this side about it."

"Because I'm really interested in aesthetics and the beauty coming out of something 184
using raw materials to make beauty and stuff like that, it was interesting when I first 185
started to work with Anne because she saw society and structures as being something to 186
achieve but I wanted to get at the real authentic Anne, to bring something out …
because she was all over the place with… the outside world, what the world demands of 187
her, not really getting in touch with who she is."

"first and foremost before she can put Tim within her art, it's about finding herself first 188
of all and then getting to what really is."

"I did a true, that's why I said fine art through process as I went through at art school 189
and I went through that same very process with Anne because I believe for me and that's 190
what's so nice about it because I could see things in Anne that I had never seen in 200
myself but then I can see how she was going through that process, how she was, you 201
know creating something beautiful but it was a struggle at the beginning"

"I didn't want her to feel that because when you do fine art you don't have that, you sort 202
of are just thrown in there so and people will try and help you but they don't want to 203
intrude on you finding yourself, you know, its all about finding yourself, what is 204
authentic about you, comes out in the work."

6

"Like you may have hundreds of different artists drawing the life model or whatever it 205
is but they're going to have different which are there, you know that's what I was 206
talking about in the social bit, you know we don't all want to be mechanical artists and 207
stuff like that, its about finding the real artist."

"In a way you just respond to her needs naturally, you know I know the process so well 208
that I don't have to think about it because ive done so many times so you just respond in 209
a very natural way and then she will respond in a very natural way to what, although I 210
don't interfere with her own creativity, you just add a little bit of this when she needs it 211
and you learn her language, its about learning her language… because she has a very 212
different language and I had to learn that language and then find how to communicate 213
some of the stuff because your reflecting back what she already knows but she cant see, 214
do you know what I mean? Back to her so she's able to draw a conclusion about it and 215
move on to different aspects of herself "

Change over time "because she's less conscious of myself, I'm just there because 216
you've built up a relationship where its, you actually feel comfortable with saying 217
whatever you want to her or vice-versa and there's no judgment there or anything like 218
that. Its just a very natural process, its not where your conscious of what your saying. 219
The same thing happens within the actual artwork. Once you start being less conscious 220
of what she was doing, let herself go and actually go into the artwork and let that itself 221
flow into the artwork because I'm not there when she does the artwork but I can see 222
each time when I come. When she not struggling, particularly with the later pieces of 223
work where she just… your conscious when you start out about it but then you just go 224
with the flow of it because your creating a language its like a dance. She knows how to 225
feel the paper, she knows how to sort of use things." Ingold

"I mean she surprises me, I'm just so envious of her now, no I really am, its absolutely 226
sublime her work and I didn't want to tell her that … but no honestly I am just so 227
bowled over with the process she has gone through and how she's handled everything 228
because to me somebody who lost someone I could identify with that work, to struggle 229
through all that darkness and then comes out with such beautiful, light, fluid, you know 230
watery paintings. Although if you really look at them, they're actually, they look very 231
fragile, very beautiful and very lacelike but they're actually, you can feel when you go 232
really close up, her thumbs being ruined by the textures and stuff like that, which is kind 233
of nice, like she's been digging in earth."

"I have to say it's a very organic process and I have to say she had to feel the materials 234
to really understand herself, you know its not an intellectual exercise… both actually… 235
its very much both mind and matter coming together and that what's really, dare I say, 236
quite cathartic about doing art, because I recognize a lot of the stuff that she's doing is 237
very much in the vein of a lot of abstract expressionism artists, you know ['Calethele 238
/Kalathil – an aritist?] stuff like that and these were people who were able to tap into 239
that area of themselves, which is very authentic to put it into the world and I feel a lot 240
was said in the work and I really appreciate and that's why I appreciate Anne's work 241
also"

A: "It feels from the beginning of the process, much more collaborative now, at the 242
beginning it was asking you how to do things, wasn't it, whereas now I'm talking about 243
it and saying I tried this, I tried that, what do you think about this and it just feels… At 244
the beginning I felt like I needed to be told what to do or guided a lot, whereas now it 245
isn't really about, occasionally there is a technical question or something but generally 246

7

it feels very different doesn't it, I feel like this is my stuff which I show to you and we 247
talk about it, whereas before it was, I've done this, is that right or have I done this right 248
or, you know how can I change that"

E: "Its like I'm talking to an actual professional, you know like your no longer a child, 249
you know like you've grown"

A: "very quickly"

E: "but it you've had the experience, you know, with the clay pots she hasn't changed 250
any of her way of working because when I saw the clay and the introduction of the 251
actual whiting and stuff, those materials which she had to mix together, its just now 252
she's just sort of doing it, doing the same thing on paper… That's when you know 253
something's really happening in the work, she isn't trying to make the work to sell to 254
people … it isn't the driving force for making art, you have to express something that's 255
why we exist"

"We call it art but at the end of the day its just our emotional insights that were putting 256
out into world and how we put it out into the world is what really heals us."

"I think its really important for Anne to go through the experience of an exhibition 257
because its about you putting yourself out into the world and putting a lot of what 258
you've been through out into the world. We have to share our experiences, sometimes if 259
we lock ourselves within our experiences… we'll keep blocking but you know I think 260
its really important because you shared these with me and I think they're so beautiful 261
and so poetic, you know particularly the last ones. I feel it would be a crime for you to 262
sort of hide them away – no seriously these are something else."

"Its just fear of going out into society but I think as an artist that's how you enter 263
society"

"But I'm never inhibited about putting my work out into the world itself. I'm inhibited 264
about putting myself into the world but not my actual work because its like, it creates 265
that barrier and I think, you know you putting your work and yourself into the world 266
gives you a way of seeing yourself slightly differently its like your mirroring," 267

A: "That's true its about seeing yourself differently and I think, again thinking about the 268
process, I think it would be good and Elwin we've talked about this in that it was all 289
about Tim, whereas now its all about me and I think that's been quite an eye-opening 270
exercise. Because I think when your grieving, especially at first it is very inward… but 271
its interesting that the kind of focus has changed a little bit so Tim and Elwin and this 272
process has allowed me to discover something about myself actually and I think about 273
myself differently. I look at these and I think, sometimes I think actually they're really 274
quite good some of them and that's a really unusual experience and I don't feel quite so 275
difficult now about other people seeing them… So there's been process and progress on 276
lots of different levels."

E: "I think its really important what you were saying about grieving because when you 277
grieve about that person you forget about yourself, you lose yourself to that grieving 278
and its about finding yourself again so you are able to understand why you have the 279
grieving process, you know because then you can move on but you know you never 280
leave it alone but its about balancing it and sometimes you can just loose youself in the 291

8

grieving as I well know… but just by putting yourself into the world you know you still 282
exist… and the person still exists within you and that's important and they're still 283
around you because your making works for them"   C.B

A: "Because when somebody dies, somebody close to you dies it changes you doesn't it 284
and I think it is about finding who you are without that person that's been a very 285
important part of the process which standing back and looking now because there is a 286
body of work, if you want to call it that I can see and like I just said, I do, it has given 287
me a different kind of facet to give myself that I would never have thought was there or 298
had the opportunity to discover"

E: "You'll discover another part of yourself within the exhibition, that's something, its 289
scary but its something that once you get through that you know you can conquer 290
anything"

"I think I've learned an awful lot through the process about myself also, I think you 291
can't work with someone without learning because your each mirroring each other and 292
in a way I'm very sad about the ending but I'm also so elated to see, watch what Anne's 293
created so you know, its like everything, like what she was doing the work for, to move 294
on you know for me its like yea I've lived that and I've had that wonderful experience 295
with Anne… but you know it isn't lost you move on and you find yourself again but its 296
such a pleasure sharing your experience"

A: "yea we've had a good time havn't we?"   297

E: "yea we've had a laugh."   298

"I think what it showed me was I havn't changed because art, all I've just done is 299
changed materials that I use as an art therapist coming from being a painter I still use all 300
the same skills but I just work with people. I no longer work with objects I work with 301
subject matter. People are subjects that matter. You know and that's what's really 302
beautiful about, you know like because I'd stopped painting after my mom's death. I'd 303
lost all the… I'm looking for new stuff to work with and its so wonderful to feel 304
somebody can go through a process of art because you know its filled with a lot of 305
theory from other professions rather then theories that it has actually grown from, 306
grown organically from an art therapy and I think this, because I wasn't actually here as 307
an art therapist, I was here as an artist and we worked professionally as artists work, you 308
know I actually go to my friends you know sometimes they will ask me '*come over I* 309
want a critique and stuff like that' and that's all it was really and I'll say well maybe you 310
need to use this or something like that but its actually exactly the same as how I would 311
work with my friends and because in many ways they're doing the same thing you're 312
trying to do. They're trying to come to terms with something, you know you don't paint 313
for nothing, your not an artist for nothing, you are trying to put these things inside here 314
that might be too much into the world [so the process is no different to what you call art 315
therapy]"

[Research should be an adventure it should be an exciting voyage into the unknown and
that is the kind of research I want to do]

Sam:

9

"So my names Sam… and the person who I am doing the project on is called Chaz, well 316
she's Charley who I loved to pieces for a very short period of time in my life. Growing 317
up we were in boarding school and we were doing our A' levels together and she was 318
just awesome and I think it was one of the first times that I had a friend that was like, 319
my friend so … being in a really strange environment and not really having anybody, 320
not really knowing anybody, her and this other girl called Charley, happened to be 321
called Charley kind of took me in and so its about her really"

"its quite an interesting question because when I think about the process of being 322
involved in the project my brain automatically spreads, scatterguns to about four 323
different areas but I suppose the thing that has been really interesting is how often ive 324
been surprised by my reaction about thinking about her and the things that have come 325
up and actually just reflecting on those really visceral human moments where 326
something's happened out of the blue and I've suddenly gone that reminds me of her, 327
why does that remind me of her? Why that and then narrowing down on those particular 328
things from a feeling state but also from intellectualized state as well and actually just 329
trying to negotiate those two parts of me and then to somehow put these things together 330
and to actually come up with something tangible that other people are going to 331
experience. So just that whole concepts been fascinating"

"And sometimes it feels like the feeling gets removed a little bit and sometimes it feels 332
very based in feeling and that can slip quite fluidly between as well so that's also 333
interested me."

"I see the object as a symbol, more so then something that has been really heavily 334
imbued with instantaneous meaning, for me the really private intimate moments have 335
been when I've been on my own and I've been musing, so for me I don't think those 336
particular nuances will ever translate to an object because that's so personal to me and 337
no one else can download my brain and heart into their viewership but its just trying to 338
contain that as much as possible in a symbol and I suppose the conclusion I came to was 339
just to completely disregard whether anybody else would get that same meaning from it 340
and actually its ok for it to just be a strange object that other people can experience in 341
their own way and it doesn't necessarily have to have that same visceral, really pure 342
meaning"

"The collaborations actually given me a kick up the arse [laughter] … I think its 343
actually been very grounding and given this structure around it which has helped me go 344
right – push forward, right – push forward, right – push forward because I am a little bit 345
scatty but then in terms of ownership, I have never felt like its not mine and actually it 346
does feel very mutual and I very much appreciate that and its something because I'm an 347
art therapist as well, thinking about my role as an art therapist but then being flipped in 348
a way where I'm actually producing something that's about me but in a context that's 349
going to be wider, I thought I'd really struggle with it and also I'm quite possessive 350
with it so I thought I would struggle with that too but not been a problem at all. None of 351
these things that I preconceived myself to have an issue with have been present 352
throughout the process, its all been really easy."

"The object has these little symbolic stories and it actually has sound bytes of these 353
stories so because I've got a Dictaphone that's actually got her voice. Charlie's voice on 354
it, with me talking to her and its literally this little time capsule from back then so they 355
are very direct little moments in time, little stories, snippets so they are literally 356
contained in the piece whether anyone else will get an overarching narrative from that, I 357

10

don't think so, but for me they're kind of like little, little condensed bits of information 358
but for me when I hear them, they expand in my brain and suddenly these things that are 359
tiny and meaningless for others … I am there again, I can see where, I can see her face, 360
I can see me talking to her, I can see the argument that happened before we did that 361
little sound bit. I can see it all, so very very dynamic for me but other people witnessing 362
it, I think its just going to be this strange stream of bibble that's going to kind of be 363
meaningless and weird but I think that's ok."

"so the making, the making's been a journey [laughter] so the making I've ended up 364
doing something that I've never done before so I had to teach myself through a little bit 365
of help from a friend who's called Charley I've just realized, that's quite interesting – 366
my other friend Charley so she's helped me how to get used to these materials which is 367
felt making, so its dry felting with a needle and I would never normally go into a project 368
thinking I'm actually going to have other people view something, with something I've 369
never actually been accustomed to doing before, so that's been quite interesting and I've 370
loved doing it."

"The actual things that I'm making are basically mushrooms out of felt and you just 371
work and work and work at them and the reason that they are mushrooms is because 372
mushrooms will forever remind me of Charley, because she's always loved them and 373
birthday cake was a mushroom, whenever we were going out on walks or sneaking out 374
of school to go and smoke, whatever we were getting up to, she'd always point out 375
mushrooms. It was mushrooms, mushrooms, you know mushroom on her shoulder that 376
kind of thing. So that was a given, that was defiantly going to be in there somehow but 377
then the actual process of making it and trying to figure out how these mushrooms were 378
going to be made, I mean that came from me trying to do ceramics in my mind to make 379
these time little decorative dainty things to painting because that's the format I'm used 380
to … and whichever route I sort of started to venture down just didn't quite resonate or 381
sit, it wasn't quite right and it was only really when I thought about the moments, so 382
going back to what I said about earlier, when I had those moments where I suddenly 383
was overwhelmed by life experience that reminded me of her … why am I remembering 384
her now? Its through that thought process of how things pop up that I thought of the 385
mushrooms again and them being rhizomes and then thinking about the repetition of 386
how you actually make felt and as soon as I made my first one I was like 'that's it'. 387
That's totally what I'm supposed to be doing and it was this **pink gaudy** [laughter] 388
cheesy little thing and I just thought that doesn't matter that's the process behind 389
actually making it actually is so rewarding and it sort of contains some of the meaning 390
in it that it just was supposed to be, it was supposed to be that despite what it looked 391
like and my judgments on what it looked like"

"I think the mushrooms was the main thread that was there the entire time and all the 392
thinking defiantly fed into that and it fitted. There were things that got dropped that 393
were part of my thinking, because I think when I first started making and thinking it 394
was almost like again scattergun – everything, so one of the schools we went to was a 395
Masonic school with crazy symbols everywhere so I was thinking do I put some of 396
these symbols in the art work. These symbols are so imbued with their own meaning 397
anyway that they kind of took away, because of the history of their meaning, kind of 398
took away from the meaning I had round the things that I was making so they ended up 399
being completely irrelevant so they got dropped. I'd also look at photos of her and think 400
about her absence so I started to paint and sketch on an iPad app around her, making her 401
absent, what was left behind, what ripple effects almost was I left with and other people 402
and those kind of things and they're all very very valid because they helped me come to 403

the conclusion of where I am now but again, I think they were part of the process, rather 404 then actually being a final thing."

"I think that, that reduction process to actually make, do and then eliminate – I think its 405 part of the collaboration, I think its part of the making process, I think its part of 406 everything actually. I don't think there would be one singular aspect of the project that 407 would relate to but actually thinking about the collaboration again… I think in terms of 408 having almost like a third person in my mind's eye looking at this has helped me be 409 objective"

"Its not almost like you have an overseer because that doesn't feel collaborative and 410 neutral, it is more that it's a friendly perspective that just pulls you out… doing 411 something that like this, that's so personal, has the potential to be really consuming and 412 if you get bogged down in it, you cant see the wood for the trees so actually having 413 somebody there to pull you out and actually in a friendly way say 'oh, lets have a look 414 at this' and even when you weren't there I could have an aspect of you with me through 415 my processing just to think of that, so it defiantly helped."

Labels: "ohh I quite like that question because I'm finding it hard to answer, so in terms 416 of actually labeling what it is, I mean its not art therapy because that's something that 417 you would have in a room with a therapist and its very formatted and contained process 418 but I found it therapeutic as well, very very much so, its really helped me think about 419 those things so I think that therapeutic aspect is very important to me so I would have 420 that as almost like a subsidiary label there… but that's maybe more to do with process 421 then an actual label. Would I call it art? Part of me would, its going to go into a gallery 422 its going to have that format so yesss… Is it the kind of that when I was training at uni 423 say its art, no. The thing that just popped into my head though is Outsider Art, it feels 424 like more that bracket then high art but also because of the way I've made it, it feels 425 quite crafty but hopefully but without that twee kind of connotation that craft can 426 sometimes come with. I know im not coming up with any answer but I think me going 427 through this like rant bllubabuba sort of explains to me how I'm finding it quite hard to 428 just label it with any particular thing."

[It doesn't actually fall easily into those categories or classes

actually intellectualizing its place in society and in a gallery is more difficult then intellectualizing or speaking about the process Polanyi

"The meticulous dismembering of a text, which can kill its appreciation, can also supply material for a much deeper understanding of it." P.19

"The things that we know in this way included problems and hunches, physiognomies and skills, the use of tools, probes and denotative language and my list extended all the way to include primitive knowledge of eternal objects perceived by our senses."]

"So thinking about the end result of actually having the art work in the gallery setting is 429 impacting the work, I think I would be kidding myself if I said it didn't impact it in any 430 way because obviously it has to be something that has palatability in that environment, 431 so and it has to be functional in the sense that it needs to transported from one space to 432 another, so there's very practical things to think about, so therefore that puts natural 433 conditions on what you are doing but that's physicality, that's fine, its more thinking 434 about jostling with my ego, in terms of oh its going to be in a gallery its got to be good. 435

12

So I have relied on my art therapy training with that and saying to myself *'it doesn't have to be pretty, feelings don't have to be pretty, the artwork doesn't have to be pretty.'* It is what it is and I've tried to dampen these things as much as possible going through because I want it to be pure, rather then this packaged thing and I think I've said to you previously that part of me looks at it and thinks its so kitsch and cheesy that I would never dream, years ago of actually presenting something like that because it doesn't feel packaged but I've just been able to kind of let that go enough [laughter] enough for it to be in a gallery and the more and more I look at them because of, you sort of make them up here [indicating chest] they sort of become nurtured, they are what they are and they will be what they will be and people will think of them of what they think of them and I am getting more and more comfortable with that as the process has gone on. It wasn't necessarily that way at the beginning but I'm getting there [laughter]"

"That also is definitely an aspect of it, judgment, I know I'm referring to Art Therapy quite a lot but in terms of that context, its just you and somebody else and the art that you've made and it's a safe environment you can talk about it and you actually have that space to articulate to somebody what the meaning is and they get it, you then have that very intimate thing or something that you've made on your own, you get, suddenly going public and it expanding from this known intimate safe thing to actually being exposed, your vulnerable, your actually talking about these things that are feelings that are vulnerable as well and it has the potential to be judged, whether its good, whether its bad, whether it had meaning form somebody, like what is it about, what does it conjure in somebody else, what do they bring in themselves to view it to make... do they put their own judgments on it, do they assume things on it, how comfortable will I be with them assuming something about me all of those concepts get thrown up when your doing something like this"

sunflower seeds Ai Wei Wei

"The exhibition as ending I think is actually quite powerful and what I mean by that is, it gives a very very definite anchor to the process being over and endings can be good, they can be bad [laughter] but I think it's a way of drawing a line under something in a very positive way and it has the potential to be really really rewarding and that's how I'm framing it, in that way and just everyone coming together and sharing their stories, the people that they've lost and actually that being really important and its about the people underneath it and your relationship to them and honoring that person in a way that you had never been able to before, there's something quite interesting for me about that."

"It's something that without this project I would have just carried on having my own musings and never done anything with it but this feels like I've really had an opportunity to really delve into it, really understand it, really think about her and my relationship with her in such a unique way and then kind of go oh ok that was what that was and yea I'm actually really looking forward to that bit and there's something pinging here about the idea of that."

"which is true I didn't get to say goodbye to her, I didn't get to go to the funeral, I found out about her death through a friend and that whole ending for me, for her was quite messy, so yea this is a way of doing it differently and addressing that and being able to do it in a positive way and say go yes, I've actually been able to say those things that I've wanted to say. Not necessarily to her face, not necessarily to myself in a funeral context but its different and it feels more celebratory then it does depressing but there is

13

definitely the notes, I mean I can feel a ball in my throat right now. There is definitely 478
notes of sadness throughout – [that's the reality but yea it's definitely an opportunity to 479
say goodbye"]

Stacey

"so my research at the time, I was trying to look into this people's data and objects after 480
they die so the things that are left online, the things about them that they've had through 481
their lives and what the kind of meaning is in that data and as I moved into the process 482
and met people at St Francis that were interested in collaborating with me and doing 483
this project it became much more about materiality and the way that the things that 484
surround us in our lives come to have meaning and the way that we can distil those 485
meanings and makings into our understanding of who the people we love were – or are 486
still to us and what they mean to us today, you know and how we make new meanings 487
out of them"

"really its been a process of *following* the research, so rather then me as a research 488
saying this is what I'm going to do and then *doing that* and doing it as a much more 489
functional project its been about a kind of creative emergent process whereby the 490
research is constructed through the collaboration, through working with people and 491
through making with people. We have made my research and the PhD and this work 492
and this gallery"

Sam: "its grown organically"

St: "its an organic, growing making process that kind of comes from somewhere and 493
produces unexpected things and I think that's been something across the board that all 494
the people who have been part of this process have talked about the surprises and the 495
unexpected things that have come out of that and I'm not separated from that as a 496
research or as someone who's working and collaborating with these people its been as 497
surprising for me the result of the research as it has for anybody else and I think that's 498
important in research today to take risks and to do things that we don't know what's 499
actually going to come out of it."

"The experience of the process has been surprising, I cant phrase it any other way, so its 500
– from going through the ethics with the hospice and the kind of labor involved, of 501
getting to the point where you are actually working with people to kind building those 502
relationships and recruiting to try and explain to people what it means to work in a 503
flexible way and how to gain that trust where people are gonna take that leap of faith 504
and say actually I want to do this with you … I want to make these things about these 505
people and I want to be part of a project that I don't know what the outcome is going to 506
be and I think that, that is a challenge but I think its been very rewarding for all of us 507
and certainly for me working with Freda and Sam and Elwin and Anne has been a 508
process of discovery and as part of the groundwork of making the project there was a lot 509
of ethical concerns of you know what does it mean to work with people when your not 510
trained in bereavement but actually its been a pleasure to work with everyone and its 511
been emotional at times, its been exciting, its been revealing about myself and 512
everybody else but its also been very real and I think that that can lack sometimes in 513
research that is done for a very specific purpose that when your doing a process of 514
redesign or working with something on patient centered experience that you can sort of 515
feel like your making this thing for this reason and that that reason can begin to 516
circumvent the thing itself, whereas because this has evolved it feels quite real."

14

"At the beginning of the process I had the expectation that I would work with people's digital archives so I had this preconception that we would begin to sort through the digital mess that all of us have in our computers and hard disks and yea obviously as part of the process of working with the hospice that changed because the people that I found didn't have those huge archives of digital stuff but I think the things that we have made can be applied in a multitude of ways to either digital or physical things and I don't think the process would differ much if we were exploring lots of digital things that there just might be different ways of creatively interpreting them and that actually what's dropped out of the process is the process itself, that is the thing that's important about what it is that we're actually doing and that using things like design school or art school methods within this context allows people to see things in different ways that aren't centered around that kind of therapeutic or clinical angle, which are very important but this offers a different mode of thinking about the people we've lost"

"I'm really excited about the potential of exhibiting these things in a gallery space, simply because again they've grown from such kind of humble beginnings so from the beginning of the sessions where we started talking about, I was talking to Freda about who Victor was and she was telling me about his life during the war and the history of their marriage and there's a kind of a sharing where you become so embedded into those people, you know those people, you know the people who have died, you know them so well that at some point you also feel the need to honor those people's lives and you feel the need to be part of this thing that is talking about death in a very different way to people's own understandings or preconceptions, particularly if people haven't experienced bereavement before and were seeing more of these diverse meanings and approaches to bereavement online, were seeing new approaches to aesthetics in the funeral industry and I think this process is somehow part of that to see the beautiful textures that Anne's been developing and this whole portfolio of works that spilling all over the household to see Freda using the clay, the material that she used for her whole life coming out in service of Victors life and to see Sam's work with the mushrooms where she producing these small encapsulated spaces that each explore something about Chaz and I think its these little moments throughout the process that gather together and make these objects something more then craft or something, they exist across a range of experiences and I hope that in the curation, when we come to the exhibition that we will be able to capture some of those experiences."

"Labeling has become a problem because as soon as you get into the gallery space it requires some form of identification: *What are these things? How do we want to present these things to people? How do we want people to experience them?* Giving them the label of art seems to inspire a certain way of reading the objects, which doesn't really reflect the fullness of the process, labeling them as craft diminishes the conceptual building and the way that we've narrated and tried to understand peoples lives and brought them into the pieces, design, again, contentious in the sense that design is not often exhibited and design prompts a certain functionality of the objects and although I do believe that the objects function, they have a function to us, they have a function to the participants in a particular way, they have a function to me in a particular way, they have a function to the creative collaborators in a certain way but that function is so far pushed from what we would normally conceive as design that to label it that way in the gallery doesn't seem to quite hold. So I think it's a good problem to have and as we go further through the process of the exhibition that actually to begin to pull out a collection of words that to speak about what these things *actually are* you know words like embodying, containing, animating, enchanting these kind of words, to me start to speak more to me about what the pieces are then labels like art or design or craft"

15

Sam: "Well just listening to you then those labels like art and craft feel quite static and imbued whereas the words you chose prior their also more process, movement, fluid-based words that actually encapsulate something not being static and actually having room for it to be more then just something" 564 565 566

St: "yea its that performativity as well that I've been noticing, there's a performativity about the objects that they're … and that's the worry about the gallery space that it does kind of frame them and set them into a place but actually its about that performativity of how people engage with the objects that is important, its that relationship that's built between you and the work, which is always at play in a gallery space but is potentially something that we've got to think about in the way that we develop that." *narrative of curation* 567 568 569 570 571

"I think what the exhibition does is it takes something very individualized, that the aim of this process was to create three very individual objects for people who have experienced bereavement but also for the dead and that actually placing these into a public context allows them to be experienced in a much wider way, so it allows what is essentially individualized knowledge to become public knowledge and to allow people to, as Sam was saying, to imbue them with their stories, add their own narratives to the objects, grow them and these objects, these things that we've have made become containers in some way for more people's stories and I think that that's quite interesting as a researcher." 572 573 574 575 576 577 578 579

"As a researcher that's quite interesting because actually what it does is it changes that aesthetic related to death and it gives people an understanding of what kind of the textures of death or … that embodiment, that process, that fluidity around love and death … that that doesn't need to have this kind of traditional aesthetic, it doesn't need to come in black, it doesn't need to come in sad and that emotionality and vulnerability of putting ourselves, all of us out there… putting ourselves on that stage is to try an circumlocute scene of those, the avant-garde, the art society and do something that is actually just about experience and it holds that vulnerability to say that this is what we've made and this is what the process is and we want *you* to have that experience of that process" 580 581 582 583 584 585 586 587 588

"This a project that I've been working on from the past 6 years, so for me the idea of the ending is incredibly important and the important thing about it is its not the ending of the research because the research is a lifelong pursuit to try and understand to try and think about what it means to live, what it means to die, how the future of death in relation to new digital environments, in relation to the world, in relation to art, design and creativity is evolving and changing [but its an ending to this process and to this collaboration and I think that there is potential to kind of see something in a new lens, in a new guise, in a new form through an ending that cant be seen in any other way."] 589 590 591 592 593 594 595 596

"The word participant is *feeling* less and less not important but less and less fitting, its feeling less and less fitting to the process and the word collaborators, as we said, it feels much better and originally because its this process of 'how do you actually write about something that you're doing' and that the division of the two words participant and practitioner was meant to give in some sense a way of writing about these two separate things that you're doing but actually the roles have intermingled and its difficult to pull apart who's a practitioner, who's a participant, what's their role in the process, who's learning from who, because we're all learning from each other, we're all involved in the process, we're all building the research and that idea of the ego, this idea that Sam was 597 598 599 600 601 602 603 604 605

16

talking about. This idea that we have to step out of our ego in order to understand what 506
it is we're doing has been really important as a researcher as well to not allow that 607
research ego to say this is *what I want to find* and this is *how I want to find it* and 608
actually just to let the process run away with itself to be leaky to be fluid to be 609
performative to embody those experiences and then at the end for me to gather them 610
together in this gallery space and say what is it that we've actually found, what is it that 611
we've actually done and how does this change the way we understand death and life 612
and bereavement and the relationship between making and that kind of conceptual 613
development within that process."

17

APPENDIX 6: GLOSSARY OF TERMS

This glossary contextualises the use of specific terms within this research. It supports these definitions with reference to the used literature.

Actor Network Theory

Actor Network Theory (ANT) is an approach to understanding systems that goes beyond the study of social networks or human relations. It does this by extending the word actor to include human and non-humans, with the aim of rebuilding social theory out of networks (Latour, 1996). This network approach to social theory transcends dualistic thinking by moving beyond two dimensions or singular factors into a collection of nodes that have "as many dimensions as they have connections" (Latour, 1996: 370). However, it is important to clarify that actor-networks are not the same as technological networks. Technological networks seek to stabilise and link all elements in an engineering sense. Law (1992) states that ANT is essentially concerned with the mechanics of power. He explains how networks can come to look like singular nodes, for example "the British Government" rather than all the things that make it up. When analyising "the British Government" with ANT, all these things, materials, figurations and systems are taken into account, building a more complex and nuanced understanding of power relations. Therefore questions of agency are embedded in ANT. This includes what agencies are evoked, how and by which actor. By doing this, theorists using ANT create a shift in our understanding of objects and things as a source of agency, where their material and social properties shift relations (Latour, 2006). ANT has given designers the scope to consider things as collections "of humans and nonhumans performing and transforming the object of design" (Telier, 2011: 6). By collecting things into a sociomaterial assembly, they are transformed into actors that challenge the role and position of design in society. *See also entries*: <u>Agency</u>

Agency

Agency is the capacity for an actor to perform in a way that affects a given environment or situation. Latour (2006) states philosophers such as Hegel and Dewey have opened the concept of agency. He defines that, to use agency as a form of analysis, it must be visible and describable (this may include the figuration of a range of actors to give it a shape) as ANT introduces the word 'Actant', borrowed from literary theorists (p.52-54). Ingold (2013) also contributes to discussions on agency by considering the way things are extended through use. He critiques the notion of agency (in both humans and non-humans), preferring the

term 'possessed by action'. In this way he incorporates the liveliness of materials and things, which are 'forever immersed in action' and so entangled that they cannot be traced back to a point of origin (p.96–97). He focuses on collaborations between people, things and materials to move from a dance with agency to a dance with animacy exploring the nature of their correspondence, where each partner may lead or be led (p.101). Whereas Malafouris (2013) defines that agency is based in neither human nor thing but lies in the material engagement of multiple parties (p.18). Walter (2013) also weighs into this with debates about whether the dead process agency or mealy act through representation or symbolism. He argues that the dead do possess agency through "wills, philanthropic trusts, genealogical surprises, reincarnation, and even … through the very materiality of the dead body itself" (Walter, 2013: 21). *See also entries*: <u>Actor Network Theory</u> and <u>Thing</u>

Art Therapy

Art therapy (or art psychotherapy) can be defined as the use of art for therapeutic purposes. This has been interpreted traditionally as either art making as a healing process, or as the use of an art product to analyse and understand the unconscious (Moon, 2010: 7). Art therapy was professionalised in Britain in the 1940s, even though art making in hospitals pre-dates it and was occurring on many sites in ad-hoc ways, with a range of accessible materials (Moon, 2010). The professional organisation for art therapists in the UK is *The British Association of Art Therapists* (BAAT). The BAAT, on their website[82], describe art therapy as "a form of psychotherapy that uses art media as its primary mode of expression and communication [where] art is not used as diagnostic tool but as a medium to address emotional issues which may be confusing and distressing." The role of art in art therapy is challenging to define, with some art therapists stating that there needs to be more understanding of how artistic practice can be used as a driving mode of inquiry in therapeutic relations (Mahony, 2010) and others stating that the introduction of crafts and a wider range of materials (Kapitan, 2011; Huss, 2010) may help to break down some of the hierarchies, both in our understanding of the arts and art therapy. This includes a re-positioning of art therapy in relation to a growing discourse on arts and wellbeing, from a medical to a social practice (Westwood, 2014: 11).

Artefact

Artefacts in the broadest sense are something made or given shape by humans. Etymologically, the word derives from the Latin arte ("by skill") and factum ("made

---

[82] The British Association of Art Therapists http://www.baat.org/About-Art-Therapy [Accessed 20th October 2016]

thing")[83]. In design terms, Tellier (2011) defines artefacts through two main perspectives: design where the outcome is a device (e.g. a chair for sitting) and design where the outcome is a thing. As a thing, design may modify spaces, alter experiences, be rich in aesthetic and cultural values and open up new ways of behaving and thinking. He questions whether even simple artefacts (like the chair) can be defined by their purpose of use or the way they inscribe actions. By using Suchman's (2002) critique of artefacts being scripted with their use, he is able to complicate these functional things. Suchman (2002) claims that technical artefacts are embodied with human subjectivity as we are performing with them, and Malafouris (2013) adds to this through his notion of lively materials, in which artefacts are not inert matter but something active to engage and interact with (p.150). Kimball (2009) extends this to advocate an approach to design practice that specifically attends to the role of artefacts, without dismantling them into either their use or material structures (of making). This corresponds to Ingold's (2013) critique of the separation between the making and using of an artefact, where the dualism defines a clear end point to the artefact. Tellier (2011) also cites that design action must evolve "until the designer achieves a satisfactory coherence between artifact and idea" (p.85) and that designed artefacts relate to a wider landscape and context. *See also entries:* Actor Network Theory, Situated Design and Thing

Bereavement

Bereavement is the loss of a loved one through death, and the subsequent grieving process. The term grief, which is often used in relation to bereavement, refers to the emotional affective response to death that may vary within individuals and across cultures (Stroebe et al, 2008). 'Grief work' is considered as one of the modes of coping with bereavement and may include activities such as meaning making and continuing bonds (Klass and Walter, 2001). This active process of grieving can be approached creatively, integrated with new technologies, performed publicly or privately and include many other forms of individualised practices (Walter et al, 2012). The concept of stages of grief or a timeline of grieving have been contested by contemporary theorists in the field of death studies (Walter, 1996) and gave ground for a new wave of constructivist grief theory (Neimeyer, 2005). This new wave sees bereavement as complex, creative and individualised with a range of practices and experiences that are significant to their particular loss. Walter (1996) defines the role of bereavement as the development of a durable biography, where in some cases conversation has superseded ritual as a

---

[83] http://www.etymonline.com/index.php?allowed_in_frame=0&search=artifact [Accessed 5th October 2016]

primary bereavement practice (Klass and Walter, 2001). *See also entries:*
Continuing Bonds and Meaning Making.

Co-design

Co-design is an approach to design that brings designers into collaboration with
non-designers (usually users). It also puts groups of people that are active within
particular systems into collaboration e.g. doctors, patients and designers. It uses
the distinct knowledge of each person to breakdown hierarchies and relinquish
control, moving away from the design expert in the formation of a design product,
service or system. More recently, co-design has been used in business, health and
social sectors (Bradwell and Marr, 2006). This has also created new models such as
experience-based design, which although discussed under the co-design grouping,
focuses more on the integration of user experience, rather than introducing
collaboration into the design process (Bowen et al, 2013). Collective creativity, as
defined by Sanders and Stappers (2008), has been around for nearly forty years
under the term participatory design, which has been developed into co-design and
co-creation. Co-creation is a very broad term, that can apply to collective creativity,
from physical to metaphysical and material to spiritual, whereas co-design is
specifically about when collective creativity is applied to the whole design process
(Sanders and Stappers, 2008: 6).

Continuing Bonds

Continuing Bonds is a theory that states that after a person dies, the relationship
we once had is not severed but continues and evolves after death. It critiques
Freud's (1922) emphasis on the necessity for the bereaved to engage in time-
limited grief work, which includes coming to terms with the loss, and moving on to
form new attachments. In continuing bonds the relationship is renegotiated rather
than detached from. This new relationship with the dead may involve: the deceased
becoming a source of continuing guidance and advice; the deceased clarifying the
personal values of the survivor; the deceased becoming a valued part of the
survivor's own personal biography (Marwit and Klass, 1995). It is important to
acknowledge that the traditions of continuing bonds have existed and been
integrated into other cultures and grief practices for many years, for example in
Japan, India or Tibet (Klass and Walter, 2001). Klass and Walter (2001) state that
conversations with and about the dead have replaced rituals in our approach to
affirming bonds, and this has created new roles for the dead within our lives, re-
socialising their presence (Walter, 2008). The dead have also been integrated with
technological systems, and continuing bonds is seen as an increasingly normal

practice online, particularly on social media (Brubaker et al, 2011; Kasket, 2012).
See also entries: Bereavement

Crafting

Crafting is a process of intuitive negotiation in the formation of an artefact using specific tools, mediums, skills and intent (McCoulough, 1998). This refers to a process that considers how the material, humanity and environment of a craft inform how we work with physical or digital materials (Richardson, 2005). It develops a creative process for working incrementally with raw materials that have no fixed outcome but a range of unfixed potentials (Alfondy, 2007). This can be enhanced by Ingold's (2013) notion of making as a correspondence between the material and the craftsman, where craftsmen are able to think through materials (p.31). It also builds on Polanyi's (1866) approach to tacit knowing as a way of trusting our hunches and skills (p.29) in combination with a sensorial approach to engaging with things. In addition to this, crafting may be used as a way of humanising technology (Wallice and Press, 2004) by extending the experiential qualities of things. *See also entries:* Artefact, Making and Thing.

Ethics

Ethics is defined as an understanding of human morality that may also refer to the application and judgement of right and wrong conduct. It is often linked to the concept of integrity within a research context. The Research Ethics and Integrity Sub-Committee at Goldsmiths states that its role is "to promote a research environment that is underpinned by a culture of integrity and based on good governance, best practice and support for the development of researchers."[84] The Research Governance Framework, used within health and social care, "outlines principles of good governance that apply to all research within the remit of the Secretary of State for Health. Research governance is one of the core standards for health care organisations.[85]" It sets out principles, requirements and standards in addition to monitoring and assessing that these standards are implemented. It is in this way that institutional ethics or systems for gaining ethical approval, like research governance, may be considered as both a practice of care and the responsibility (liability) of the institution that governs the research to ensure that the researcher is fully prepared to navigate the research confidently and

---

[84] Research Ethics and Integrity Sub-Committee at Goldsmiths:
http://www.gold.ac.uk/governance/committees/researchethicsandintegritysub-committee/#_ftn1 [Accessed: 18th October 2016]
[85] Research Governance Framework for Health and Social Care (2005)
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/139565/dh_4122427.pdf [Accessed: 24th October 2016]

understand the needs of those involved (see App.2, p.172 for further documentation about how this research has been ethically realised).

Making

Making is a process of construction that forms a relationship for working with materials. Ingold (2013) describes this relationship as a correspondence, closer to a dance, where the maker does not impose a pre-conceived form on raw materials but brings forth their potential as a form of 'becoming' (p.31) which taps into the "sensory awareness of practitioners" (Ingold, 2013: 7). McCullough (1998) also describes the affordances of particular materials and their relationship to tools, skills and intent, and he develops then into a specific instance of making called crafting. Tellier (2011) develops the connection between making and crafting by considering the foundational role of the craftsman in making. This includes how their care, personal judgements and dexterity in engaging with materials are core in forming the artefact they are making (p.81). Giaccardi and Karana (2016) have also expanded this discourse by introducing a new framework for making with digital content. They present this approach to material experiences by incorporating digitality in sensorial, affective, interpretive and performative ways. They claim that understanding material experience will create new modes of designing digital artefacts and that material choices create new forms of interaction. *See also entries:* Artefact, Crafting and Materiality.

Materiality

Materiality may be considered as the quality of being composed of matter, or refer to the characteristics of a particular material or thing. It is a contemporary word that builds on definitions of 'matter' and 'material' and responds to the complexity "of diverse factors in the digital age, in which 'material,' … like sound or language can now also be something that is not physical" (Lange-Berndt, 2015: 14). Katherine Hayles (1999) states that although materiality has been acknowledged it has also created a "postmodern ideology that the body's materiality is secondary to the logical or semiotic structures it encodes" (p.192). She advocates an understanding of materiality that moves beyond the body and is rooted in the subjectivity formed, by combing the materiality of informatics with the immateriality of information. Richardson (2005) supports this stating: although traditional materials have qualities such as solidity and uniqueness, the digital may be considered for its temporality and formlessness. This creates a digital material that may be crafted through programming. Lange-Bernt however sees all materials as temporal in their substance. They "are always subject to change, be it through

their handling, interaction with their surroundings, or the dynamic life of their chemical reactions" (Lange-Berndt, 2015: 12). This bridging between materials and materiality allows the properties of the digital to emerge as part of a material investigation. Miller (2010) uses the notion of materials 'interaction with their surrounding' to consider the digital as a way of extending materiality as a more flexible 'interaction' through performativity. He defines our understanding of screens, software and the body as a way of producing new surfaces and frames that combine with the senses to create more possibilities for thinking (p.232). In design practice, Telier (2011) defines materiality as a precondition that promotes creativity through engagement with "different materials, media, and representational forms... conveying and exploring different (conceptual, technical, aesthetic) aspects of design" (p.30) *See also entries:* Crafting and Making.

Meaning Making[86]

Meaning making in psychological terms is a process of constructing or making sense of a situation, life event, person or yourself. In terms of bereavement, it is an activity (sometimes defined as grief work) that involves the construction of meaning around a significant death or loss (Neimeyer et al, 2006). It is closely linked to sense making and benefit finding. These activities all centre on the personal (and sometimes creative) construction of understanding about how and why that person has died, including what they mean to you now that they are dead. This search for a person's meaning to you after death can also be approached through continuing bonds and the significance found through the newly constituted relationship. Meaning making is part of a movement towards a constructivist approach to bereavement that rejects grand theories with the aim of viewing bereavement in a situated way that responds to a persons own understanding of what they find meaningful about the death and life of that person (Walter, 1996). It enacts a more complex and contextualised approach to making sense of a death that responds to our surroundings, social and cultural background. It identifies the need to find meaning, which can be integrated into the personal life story and biography of the deceased (Neimeyer et al, 2014). Some scholars see this as "a new paradigm of grief that views meaning reconstruction as the principal task in coping with a loss. This approach views human beings as inveterate meaning-makers, weavers of narratives that give thematic significance to the plot structures

---

[86] References only used in Glossary: Neimeyer, R., 2005. Grief, loss, and the quest for meaning: Narrative contributions to bereavement care. Bereavement Care, 24(2), pp.27-30 and Neimeyer, R.A., Klass, D. and Dennis, M.R., 2014. Mourning, meaning, and memory: Individual, communal, and cultural narration of grief. In Meaning in Positive and Existential Psychology (pp. 325-346). Springer New York.

of their lives" (Neimeyer, 2005: 28). *See also entries:* <u>Bereavement</u> and <u>Continuing Bonds</u>.

Practice Research

Practice Research aims to unify the range of terminology describing the relationship between practice and research. It highlights the breadth of practices that exist, in which the researcher is intrinsic in leading to new knowledge and understanding. It expands upon a range of conflicting terms including 'Practice-based Research', 'Practice-led Research' (Grey, 1996) and 'Practice as Research' (Nelson, 2012). 'Practice as Research' is perhaps the closest of these in which Nelson takes into consideration how practice is the mode of inquiry and requires a specific form of knowing-in-doing (p.8-9). This is reflective of Polanyi's (1966) understanding of tacit knowing, in which the researcher must engage with the site, practice, material et al before being able to work with it. Jefferies (2012) also states that practice as research has become embedded in practice researchers' methodologies, which are able to support and situate the self within the practice (p.75). Goldsmiths developed the term 'practice research' within their program of postgraduate research seminars (Jefferies, 2015[87]). These seminars aim to "generate discourse and discussion around the many forms of practice research that currently exists … [and the] need to be able to articulate the ambition of … practices in a variety of ways." It identifies the fact that practice researchers often develop their research questions along-side their practice from a context of rigorous literature review and engagement with the wider creative and cultural contexts. It also highlights that research outputs may be diverse, including but not limited to exhibitions, performances, films, creative writing, community projects et al, but not to be confused with public engagement, which happens after the research has been done. *See also entries*: <u>Public Engagement</u>.

Public Engagement

Public Engagement is the positioning of research outcomes in conversation with the public. It aims to initiate a two-way process of shared listening and interaction to create mutual benefit (Van Bekkum et al, 2016). This is a very broad definition, however, as in practice the term public engagement is enacted and positioned in a range of different ways across the arts, humanities and sciences. In the sciences, there is much debate around whether to include public-facing activities like engaging with the press or giving a lecture within public engagement. In this case,

---

[87] The Practice Research PhD Forum Sessions were funded by Concordat in 2016/2017 to run as a series of 'training' sessions throughout the academic year, focusing on ethics, life writing, rigour in research et al. I attended a selection of these sessions, which helped to consolidate my approach to practice research.

the term engagement is extended to mean anything that affects the public or changes their worldview. They argue that this can be achieved though a one-way dissemination of knowledge (Van Bekkum et al, 2016). Within the arts, public engagement also varies in the level of interaction expected from the communities. This ranges from giving voice to specific issues, challenging people's perception through artworks or working in communities contributing to economic growth and social challenges (Keaney et al, 2007). Design is similarly placed, with speculative design using galleries and other public forums to engage the public to think more deeply and question their relationship to technology (Dunne and Raby, 2013), while co-design and situated design both focus on acting within specific groups or communities to design systems, services, tools or products that respond to the lives and needs of those communities (Bradwell and Marr, 2006; Simonsen et al, 2014). Practice research is well placed to consider public engagement as a two-way process of interaction, as engaging with the public may actually evolve the research and research questions (Jefferies, 2012). *See also entries*: <u>Speculative Design</u>, <u>Co-design</u>, <u>Situated Design</u> and <u>Practice Research.</u>

Situated Design

Situated Design is a design process that is focused on building an approach and understanding of design from the locus of production, constructed through the specific conditions of the site. Suchman (2002) encapsulates this as a move away from objective knowledge. She challenges the concept of design from nowhere, which seeks to answer problems en masse, cut loose from their sites of production and shifts the focus to multiple, located, partial perspectives that are able to locate their unique character through debate (p.2). Simonsen et al (2014) develop this further through focusing on design's ability to produce new insights and theories through interventions in messy real-life circumstances (p.45). This is connected to the development and opening up of art and design, which can be used as tools for improving participation and civic engagement (Simonsen et al, 2014: 182; Keaney et al, 2007: 12). Suchman (2002) also sites an ethical stance of situated design, whereby it seeks to recognise boundaries, problematise them, engage with them, maintain them or work across them forming an approach to design, which navigates and negotiates specific relations. It is in this way that the site is engaged with and may be considered as an actor in forming the design process (Neisig, 2014). *See also entries*: <u>Actor Network Theory</u> for further discussion on actors.

Speculative Design

Speculative design is a way of considering how design's function may shift if it moves beyond the pressures of a commercial market. It looks at future scenarios or alternative realities and constructs things that speak about these worlds. Through these fictional design products or scenarios it creates imagined narratives for the viewer. Dunne and Raby (2013) state that thinking about the future through design can be used as a tool to better understand the present. To construct these narratives, it borrows from cinema, literature, science, ethics, politics, and the arts. Speculative design develops upon 'critical design', which was defined by Dunne and Raby in the mid-nineties (2013) they explain critical design through the example of William Morris (p.17). His approach to craft within the construction of his furniture critiques technology and may be considered as one of the first critical design objects. It does this by incorporating the values of Morris into the furniture, which are intentionally at odds with prevalent manufacturing and production processes in the 1800s, providing relevant critique. Speculative design moves beyond critical design in its construction of fictional worlds and functional re-imaginings of technologies. It locates itself as public engagement; it must be disseminated through exhibitions, publications, press and the internet order to perform its function (Dunne and Raby, 2013: 139). *See also entries*: Public engagement

Thing

Things can be defined through their etymology[88]. The origin of the word thing derives from the old English *þing* or Old High German *ding.* These words refer to a council or assembly and over time they referred to the being or matter itself that was collectively deliberated. A *Thing* has also been used to define personal possessions from c. 1300. A rich interdisciplinary discourse surrounds things, which has been discussed in depth in Chapter 2 (p.40). In summary of this, things allow for a permeable state between subjects and objects, the fact that people are things too allows for an overlap between personhood and thinghood (Ingold, 2013: 94). Things also create people (Miller, 2008) and may be used as a tool to think with (Henare et al, 2007; Turkle, 2011; Malafouris, 2013). However the nature of things is also debated in terms of whether they possess agency and how their materiality may play a role in this (Ingold, 2013). Latour (2004) argues that both manufactured and handmade things may become matters of concern, through Actor Network Theory, which allows for their complexity to emerge through the networks they enact (Latour, 2004: 158-159). In design, the understanding of

---

[88] http://www.etymonline.com/index.php?term=thing [Accessed 14th October 2016]

things as a gathering challenges the design community to open them up to a wider social engagement (Telier, 2011: 2). *See also entries:* <u>Agency</u> and <u>Actor Network Theory</u>