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Co-curating as caring: an exploratory study within a cancer hospital.

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by

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Abstract

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Doctor of Philosophy

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Co-curating projects have involved people collaborating to create exhibited artwork displays. These collaborative exhibitions have been created for audiences such as those in health settings. Little has been known about such co-curating projects within hospitals caring for people with cancer. This thesis is a thematic exploration of the processes and experiences of cancer hospital exhibition co-curating as caring. An adapted qualitative study design explored a hospital co-curating project with a group of young adult patients and reflecting around two generated themes of caring associated with the project. The thematic exploration's original contribution to better understanding the processes and experiences of cancer hospital exhibition co-curating as caring, and to better understanding co-curating as caring more widely, are visualised and discussed.

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Research Thesis: Declaration of Authorship

Print name:

BENJAMIN JOHN HARTLEY

Title of thesis:

Co-curating as caring: an exploratory study within a cancer hospital.

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signature: Date: 14/2/2025

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Abbreviations

APPG	All-Party Parliamentary Group on Arts, Health and Wellbeing
COVID-19/covid	Coronavirus disease 2019 caused by the virus SARS-CoV-2
CQC	Care Quality Commission
EBCD	Experience based co-design
ERGO	(University of Southampton) Ethics and Research Governance System
GLA	Greater London Authority
HAPM	Hospital arts programme manager
MRC	Medical Research Council
NCCH	National Centre for Creative Health
NHS	National Health Service
PIS	Participant information sheet
PP(s)	Patient participant(s)
QD	Qualitative description
RTA	Reflexive Thematic Analysis
UK	United Kingdom
US	United States
WSA	Winchester School of Art
YSC	Youth support coordinator

Key definitions

Caring – promoting autonomy in the context of supported living.

Co-curating – people collaborating creatively to make exhibitions that the public encounter.

Reflexivity – a process of disciplined self-reflection.

1. Introduction

1.1 Introducing the author

In this chapter I, the thesis author, introduce my personal context as a trainee health sciences researcher. I also provide the reader with an orientation to how my thesis has been organised.

At the time of authoring this thesis I was a forty something UK-born mixed-white male living in London. I did not have a cancer diagnosis. In addition to my prior health services administration, nursing, and social science academic experience I'd completed an art and design foundation course and a fine art graduate diploma. In 2017 my combined qualifications and experience enabled me to obtain partial funding from two sources to begin my PhD, with cross-disciplinary supervision from the University of Southampton's School of Health Sciences and Winchester School of Art.

Prior to and whilst conducting this research I was employed at a National Health Service (NHS) cancer hospital Trust as the arts programme manager. I had joined the hospital as a cancer survivorship team project nurse in 2013. My employment as the hospital's first substantive arts programme manager grew as the nursing project work had ended.

In my three days per week as hospital arts programme manager I managed a portfolio of half a dozen arts projects. These projects involved professional musicians and artists working with the hospital's patients, staff, and visitors. A core project area for the arts programme manager role was taking care of the hospital's displayed collection of artworks and co-creating temporary exhibitions relating or responding to that collection, with hospital staff, patients and visitors.

The report Caring for NHS Art (Meaker, 2010) had provided insights into the unique challenges faced when managing, or "curating", such collections of hospital artworks. The report's insights included that we were curating in busy settings that were not designed for art collection displays, and where people may experience art differently to when in a museum and gallery (Ibid).

I sought to explore and better understand the complex nature of these curating activities by crossing the boundaries of both arts and health through research. Another rationale for my exploration was that, as someone already curating with groups of people in a cancer hospital, I may have been able to better understand my practice from multiple points of view, within that setting.

In line with my earlier explorations as a nurse, I also sought research approaches that considered myself and the people being researched as complete individuals (Henry et al, 2014, Olsson et al, 2013). I selected an ethnographic way of researching my own personal observations and my observations of the people I engaged with, to try and understand the complexity of the curating we undertook together (Dougall et al, 2018, Hulks et al 2017, Ham 2017, Seale 2016). The base unit of this exploration was intended to be me, the author (Cooper & Lilyea, 2021). The purpose of my thesis was to be one that could transport the reader on an authentic articulation of my own and others' processual experiences whilst I was facilitating co-curating in my cancer hospital, with a view to understanding and improving that aspect of my hospital arts programme management practice.

It was difficult to claim a well-informed curatorial process or approach when beginning the research, as there was a blankness of curatorial history (Obrist, 2011). The word curating came into English use from the Latin *curatus* and *cura* which meant "to care" however definitions of the word were many and varied. As with the museums in which it originated, curating was a modern European invention with a century of grey literature of manuals, policies, and procedures that practitioners were expected to refer to. Even a Curator's Handbook acknowledged that it had been a widely applied yet difficult practice to define (George, 2015).

Robert Hooke had been the Royal Society's first *curator of experiments* in seventeenth century England. Perhaps because of these beginnings, the word curator had come to conceive someone "caring" for a museum artwork collection (Basu & Macdonald, 2007). After the Second World War, museum expansion brought diversification and specialisation, with new roles such as collection managers and conservators taking over curating duties. Temporary exhibitions gradually became more the focus for a new curatorial experimentation (Norton-Westbrook, 2015).

Experimental curating at the time of authoring this thesis did not then define itself as simply exhibiting collections, though may have included it (O'Neill, 2012, Obrist, 2011). Curating could also mean thinking about art by collaborating with artists (Morgan, 2013). These experimental curatorial *co*llaborations included reinterpreting artworks and making shared decisions around how they have been manifested spatially, negotiated contextually, and mediated publicly (Chong Cuy, 2013).

Most contemporary concepts of experimental curating still encompassed such editorial selections and presentational decisions involving others. Recent decades had also seen more publicly oriented (or "co-") curating projects in the museum sector designed and measured for impact on multiple experiences (Museum Next, 2023), and suggested that curating processes offered something that "created" those experiences and "cared" about them (Arnold, 2015).

Returning to the caring root of *cura*, contemporary curators within the museum and gallery sector had also acknowledged that curating had derived from other practices such as those of the doctor and nurse, who tended and cured (Oguibe, 2001). The nursing profession had also historically acknowledged the importance of artwork on the patient experience of hospital care (Florence Nightingale suggested that the effect of beautiful objects and especially the brilliance of colour on sickness is unappreciated – 1859/American Association of Colleges of Nursing, 2019).

Whilst there was no obvious link to be found between the curating of artworks and nursing practice however, these historical sentiments were echoed in more contemporary research which suggested that artworks contributed to patients in a cancer hospital socialising better there whilst also staying connected to the world outside (Nielsen et al, 2017). Also, that artworks in hospitals helped with reducing stress for people with cancer, as patients in hospital, such as when they included calming riverine or marine scenes (Fudickar et al, 2022) and other natural environments (Lankston et al, 2010).

UK arts organisations had advised that hospitals should increase art displays and involve patients and staff in making decisions around them (Paintings in Hospitals, 2018, Arts Council England, 2007). Who should be organising these projects as *co*-curating, and any affect they may have, was less clear (NPAG Arts, Heritage, & Design in Healthcare Network, 2019, Meaker, 2010, MacNaughton, 2007). Thus, I began my research journey knowing that little work has been conducted to seek new knowledge around the experiences of co-curating art displays with patients in hospitals.

Having studied sociology before nursing, I'd been encouraged that co-curating had also been considered by social scientists as a uniquely investigative activity (Back & Puwar, 2012a). Anchored in what had been termed *live methods*, co-curatorial research activities built on a range of exhibitionary methods to explore complex questions in dynamic ways. The sociological influence on the design of this research at the outset was to help define that, for me, co-curating would be understood as *people collaborating creatively to make exhibitions that the public encountered (*Ibid).

As said, my experience as a trainee researcher prior to my PhD had been in nursing where research was considered "an activity of practitioners" (Schön 1983, p308). It may be understandable to the reader that my researcher positionality at the outset, what I knew and believed as a hospital arts programme manager (Jamieson et al, 2023), was influenced by that prior nursing experience.

Curating was mentioned briefly as an aspect of the arts programme manager role in the NHS (Healthcareers, 2018), yet research was not. Nothing was offered to explain what potentially positive experiences the practice may generate beyond saying that people seemed to *enjoy* engaging in co-curating as an activity in hospitals. As a knowledge-seeking practitioner, I strongly felt that exploring the experiences around my newly discovered area of practice was necessary (Fancourt, 2017, Daykin & Joss, 2016).

Beginning this PhD had led to my questioning how explorations such as my own could matter more widely, as new knowledge. As I discovered, any question of addressing a gap in or contributing to knowing needed to be clear about what knowledge is, how it may have been acquired and contributed as new. I found that how people experience and understand the world, as a philosophical construct, was vigorously debated by scholars. Concepts shifted over time as assumptions and beliefs were challenged. Individual ways of understanding had been social constructs of their time and were dependent on people's beliefs and values as well as the societal rules to which they adhered.

I had learned that the question of what knowledge *is* could be conceptualised and articulated as one of ontology. Ontology has been the theory of being, of reality, and of what we can know. Although the articulation of ontology had been attributed by scholars to the philosopher Christian Wolff (1679-1754), concepts around the basis of reality were central to a line of philosophies stretching back to antiquity, including the work of Aristotle (384-322BC).

Often discussed together with ontology, epistemology had been the concept of how we can know reality, and of what we can produce as new knowing, or knowledge. The articulation of epistemology as acquisition of knowledge has derived from the Greek words episteme (knowledge) and logos (reason). My consideration of these concepts and constructs led to new understanding that this research was to be a largely epistemological endeavour. I sought to discover new ontological outcomes through the process of research itself. In doing so I had taken an objective view, believing that the reality studied was independent of my individual knowledge of it.

In understanding that knowledge and meaning was something I objectively constructed, rather than discovered, I adopted a social constructionist epistemological position at the time of writing. Four ways in which I did this were by adopting a critical stance towards knowledge as a concept, by approaching knowledge as something that was historically and culturally contextual, by believing that knowing as truth has been constructed by social processes, and finally by understanding that knowledge and social action have occurred together.

This adopted approach acknowledged that the people involved in the research, including me, could construct reality in diverse ways. The approach also acknowledged that different people, even in relation to the same phenomenon, may construct meaning in their own way, and that the one person's constructed meaning may not necessarily have been shared by another person. That constructivist positionality situated me, the objective researcher, as an “active agent in the production of knowledge” (Trainor & Bundon, 2021 p3).

Corina Oprea’s (2016) PhD thesis had explored the links between knowledge production, collectiveness, and curating. It had asked what forms of collective knowledge curating produced, focusing on curators who utilised research processes and collective approaches towards knowledge production and its representation. Oprea had argued for curating that expanded beyond an act of visual representation by art, objects, facts, and ideas to “territory of congruency and/or conflict, where meaning is produced and debated” (p9). These findings suggested that my co-curating PhD research could produce new collective knowledges, perhaps through some disruption.

Sibyl Fischer’s (2013) earlier PhD thesis had also described how any affinities between curating and caring had perceived to have been eclipsed. Although a definition of caring was avoided, by looking at a variety of the case studies, Fischer had instead found relational aspects of responsibility on multiple curatorial levels. Postulating that curatorial practice remained a “caring” practice, Fischer’s findings also provided encouragement to know more about how my curating may operate on a caring level.

Whereas positionality referred to this belief structure I had begun my research with, reflexivity referred to how I had been influencing my research process and what I had planned to do with any new knowledge gained from it (Jamieson et al, 2023). Again, as I begun the research with a positionality that had been influenced by my previous career, I also adopted reflexivity chiefly as a *process of disciplined self-reflection* (Wilkinson, 1988) and an explicit evaluation of myself (Shaw, 2010) to maintain an awareness of that influence.

My reflexive stance was to be that people construct reality contemporaneously, and no one person’s account, such as observing researcher’s or observed participant’s, was to be valued over another (Woolgar, 1988). By also including others’ reflections within my research, I’d aimed also to achieve the positivist goal of accurately reporting my research participants’ accounts of reality.

In the accounts that follow I, as hospital arts programme manager (or HAPM), operated as the primary voice. I operated as a secondary voice for others who take part, by providing direct quotations and images of their contributions (after Guba & Lincoln, 2005 p196), and did so to achieve verisimilitude and authenticity. Where I’d included unusual phrasing, my intention in doing so was to enliven events for the reader (Holt, 2003). My rationale for providing such a rich array of voices was to open a space for you, the reader, to consider their own interpretation of what constituted the phenomena under exploration, building upon the subjective interpretations I offered.

1.2 Introducing the thesis layout

Having introduced myself and my positionality, in this next section I introduce the layout of the thesis. My thesis is made up of six further chapters that explore the processes and experiences involved in co-curating cancer hospital arts exhibitions. In Chapter 2 I go on to review the evidence base in relation to my focused field of study. I establish that little is known about co-curating projects within hospitals providing cancer care.

Having then formulated my research question, in Chapter 3 I take the reader through the steps chosen to conduct the research, including the adaptation of auto-ethnography as my approach. I also explain the other ways I strengthened my exploratory research methods, in Chapter 3, including by creating a study design that explored co-curating through a research project I titled "VisualBeats", and facilitated with a group of young adult cancer patients at the hospital.

From Chapter 4 onwards I lead the reader, in response to the VisualBeats project data, through my generated findings. Presented initially as descriptions and analytic visualisations, these findings are then explored as l reflections around transcriptions of, and reflections around, the VisualBeats workshops and exhibition (in Chapter 5), before offering a further exploration of the processes and experiences of as themes (Chapter 6). Lastly, in Chapter 7, I discuss the contributions of my exploration, alongside its limitations and suggest how we reach a better understanding of hospital arts programme management because of my inquiry.

2. Review

2.1 Introducing my review

In this chapter, I discuss a review of literature that took place before the VisualBeats project at the heart of this thesis was designed. The initial literature review helped to organise the key concepts that I wanted to explore in the thesis and highlighted prior research in my area of interest.

Having been a trainee nurse researcher, I naturally began viewing the subject of investigation, co-curating, through a nursing lens. Accordingly, the chapter will describe an initial systematised review of the health sciences evidence base that was carried out to find articles concerned with co-curating practices within healthcare settings. Each article found was reviewed in turn, for reasons explained, before the articles were considered together as a body of evidence. Gaps in the evidence were identified and used to formulate a research question and objectives for the PhD.

Preparing for his initial literature review also included me rethinking my experiences of curatorial projects that I had previously facilitated within the cancer hospital at the heart of the research. Including a discussion around these local projects would, I'd hoped, provide the reader with some additional contextualisation for my new explorations.

2.2 Preparing

In preparation for the literature review, I purposely considered gaps I had found in my own curatorial knowledge at the outset of this PhD. Any gaps in knowledge around theory and practice like this had been postulated as being between thinking and doing. Thinking had been described as *know that* knowledge – descriptive, explanatory, contemplative, and rational. Doing had been described as *know how* knowledge – complex, intuitive, and performative (after McKenna & Slevin, 2008, Rolfe, 1998). My rationale for conducting this additional early review of my personal practice was because it had felt important to me to outline any gap between my *know that* and *know how* knowledge as my PhD began.

Again, it felt important to acknowledge very early on that my background was health- rather than arts- based, and that this had inevitably influenced my hospital arts programme management (HAPM) practice. This was perhaps an unusual place to begin my exploration from. Having some form of arts background had been said to be the most common feature amongst hospital arts programme managers (NPAG Arts, Heritage, & Design in Healthcare Network, 2019) and this may even have been expected for those in the role (Healthcareers, 2018). As mentioned earlier, I had brought a later in life fine art education to my own HAPM role but my prior experience of curating withing the wider art community had been extremely limited.

As part of that fine art education, I had learned of and been inspired by John Latham’s Artist Placement Group who had matched artists to industrial settings, in which they co-curated exhibitions (Ian Breakwell’s work 1978/1979). In the late 1970s the community art movement had countered this embedded approach, with attention switching to marginalised social groups being empowered by artists through co-curating practices (such as Ed Berman's Inter-Action in London).

The 1990s, I‘d also learned, had heralded community research “projects” including self-organised activist groups, participatory and socially engaged art, and experimental co-curating (Bishop, 2012). The emphasis, then, had come to be on communal creative collaborations that responded to a pressing proposition or theme. Crucially, I’d been delighted to discover, the co-curated public-facing exhibition had been transformed into a site of active “social production”.

Co-curating continued developing with community-based elements into and beyond the 1990s (Obrist, 2015) and did so in even more “socially democratic” ways (Gaitan, 2013, Martinez, 2013). Most of these, I’d found however, relied on one founder (very often a “curator”) who led the groups of “co-creatives” (Mabaso, 2016). It was not clear what behaviours were involved in doing so. Talking about community cocurating more recently, Director of The Showroom, London, Elvira Dyangani Ose in *Curating as Caring: Tending to Partnerships Between Artists and Communities*, 2022, had said “fast-forwarding centuries into a much more specialized field—which includes curating artists, philosophers as curators, curators as artists; the institution of a canon (Western canon, primarily) and the multiple attempts for its distortion; various waves of institutional critique; the renewal of certain narratives to bring about change and inclusion, etc.—the figure of the curator still involves a lot of caring”. Being a nurse as well as a HAPM, this developing new thinking about “caring” curatorial behaviours had also inspired me towards further exploration.

At the outset of this research, however, more painterly aspects from my fine art education, such as community arts engagement and making site-specific artworks, had perhaps influenced my hospital curating practice and projects more. Those projects, described next, took the form of workshop-derived collaborations involving patients, artists, and myself as HAPM.

In 2018 my project Where To Look had invited students from University of the Arts London to create and exhibit artworks for patients in an area of the cancer hospital where they may have experienced distress. As my first curating project whilst in both nursing and HAPM roles, I had asked the students to consider the experience of having blood taken to see if they have cancer. Clinical staff engaged with the project as they were keen to see if the blood taking experience could have been improved using these more artful approaches.

By creating a meditative book of images and words and by curating discreet abstract art objects as visual devices in the room, the student artists aimed to distract the patient from potentially unpleasant aspects of their treatment. People’s reactions to the curating intervention had been mixed – the mostly young adult artists embraced such an opportunity to connect with a hospital exhibition viewing audience intimately, however the staff members had been perplexed by the artworks offered as solutions, finding them to be too subtle to provide real distraction.

The following year, in 2019, another art exhibiting intervention led by me and named Not Another Leaflet emerged from a wider allied health professional-led project Physical Activity For People Treated For Breast Cancer. Building on the reaction from staff to Where To Look, in Physical Activity For People Treated For Breast Cancer, patients had been invited (on the allied health professionals’ behalf) to present their service improvement ideas through a series of collage vignettes. For this project, the artworks had been created by art therapy staff in discussion with the patients involved and presented back to other patients through an in-hospital exhibition.

Feedback had been sought from patients whilst the display material had been created, and after the Not Another Leaflet exhibition. Although patient feedback was that the exhibition accurately conveyed their experience, patients had also questioned why they were not encouraged to collaboratively (co-)create the artworks. This apparent confusion around any creative curatorial role for the patients' taking part, I found, had been supported by evidence from other collaborative arts and sciences projects that reported that same occurrence (Roughley et al, 2019).

In response to the questions raised by Not Another Leaflet and Where To Look, I had begun to think about how co-curated visual arts can be a successful adjunct for exploring health experiences (Bleakley, 2015). An exhibition-making project brief was then developed with patients from the young adult ward alongside graduating art foundation students from the local University of the Creative Arts campus.

For that follow-on project titled Picking Up The Pieces the student artists had met with the young adults where I facilitated a discussion about their experiences of a clinical space - the radiotherapy department. Earlier feedback from the Picking Up The Pieces project had been that the patient's felt unwelcome in the space (which has separate areas for children and adults). The student artists functioned as creative mediators and worked in partnership with the patients to agree and create a collective abstract portrait of the patient group for it. Feedback had been sought from other young adult radiotherapy patients, and staff, who applauded the aesthetic qualities of, and meanings behind, the Picking Up The Pieces installation.

Importantly to me, then, the young adult patients had fed back at a final Picking Up The Pieces workshop that the opportunity to collaboratively create artworks for public display had felt inspiring and important to them in terms of directly representing their individual experiences. This feedback had then sparked my idea for further research into collaborative display-making, which I'd loosely conceived as co-curating. Put simply, I wanted to explore further what was involved in the experiences of a patient's created image or object being exhibited in a space in which they were "cared for". I began thinking about the function of curated artworks in hospitals, something that had been happening since the Middle Ages (Clift et al, 2021).

I found that the contemporary rationale for providing engagement with artworks in NHS hospitals had been to improve patient's overall experience and reduce pressure on other resource-intensive services such as psychological support (Warran et al, 2018). This was interesting because my own experience had been that engagement with my own hospital artworks appeared to be both fleeting and subjective. For some people, the artworks were not appreciated at all. My experience was echoed by others who found that artworks within hospital spaces had been perceived as less important than comfortable chairs, magazines, and televisions (Zook & Sailer, 2022).

Guidance for how artwork might better engage people with cancer were rare, with those available suggesting landscapes and nature scenes may be preferable to abstract paintings and portraits (Cusak & Isles, 2010). Again, this had not necessarily been my own experience so far. Apart from a short survey several years ago, staff, patients and visitors at the NHS hospital where this research was to take place had not been formally involved in co-curating artworks for better engagement.

That hospital, the Royal Marsden NHS Foundation Trust, had opened its doors in 1851 as the world's first hospital dedicated to cancer diagnosis, treatment, research, and education. The Royal Marsden now operated from two hospitals in London UK and was considered one of the world's top five specialist cancer centres (Oberst, 2019). The projects described above, unless stated otherwise, had been displayed in one of three temporary exhibition spaces within the Royal Marsden's Sutton hospital community, usually for two or three months at a time. Figure 1 (below) is a map of that site at the time of this research.

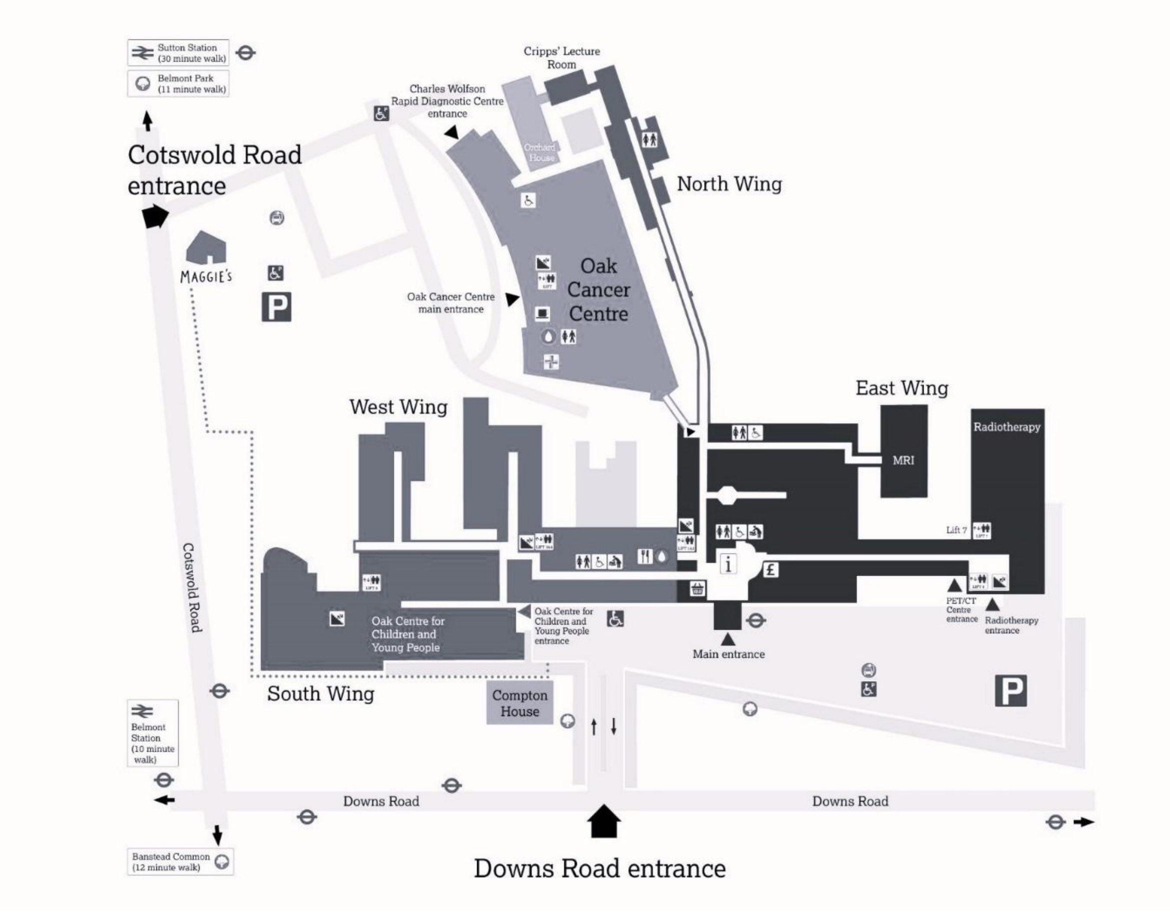


Figure 1 Map of The Royal Marsden Hospital Sutton community

Apart from the preparatory work that formed the projects discussed above, any potential for my HAPM role to support patient experience had not been explored in any detail through the temporary exhibitions described above. It was not until I had become aware of one pioneering project outside the hospital that I began to consider the possibilities, and research opportunities, that temporary exhibition spaces may be able to offer.

Sociologist Cath Lambert's and artist Brian Lobel's Fun with Cancer Patients project (Lambert, 2016) offered opportunities for a community of people with cancer to engage the public with different discourses and subjectivities around their cancer and its treatment through, creatively collaborating and making and exhibition. The project had formed part of an arts festival in Birmingham (UK) in 2003 and had consisted of workshops in which the artist had worked closely with sixteen young adults who were undergoing, or had recently completed, treatment for cancer.

For the Fun with Cancer Patients exhibition, the artist (Lobel) had shifted focus away from his own experiences as a former cancer patient to working with the young adults living with or beyond cancer, by instigating a series of creative actions aimed at helping them to process or explore their diagnosis as a community. The young adults had then generated artworks that communicated their varied experiences of cancer and cancer treatment, to the public.

Six of these interactions had been realised and documented using films, photographs, and texts, aiming to reproduce the experiences. An ethnographic approach was selected for analysing Fun with Cancer Patients and that had involved gathering field notes and interviews by a sociologist working adjacent to, but integrated within, the exhibition. The research had also included a blackboard for recording live visitor comments, with that changing content also gathered as data.

By identifying and working with cancer patients, Lobel's and Lambert's research project may, I'd noted, have been one of the first to imply a caring co-curatorial relationship with the young adult participants receiving cancer treatment. This had been hugely inspiring for me to discover as a trainee researcher in the field. Lobel's and Lambert's research problem, considered against the backdrop of my own developing literature review strategy, had offered a possible "blueprint" for my own co-curatorial research design.

Being co-curatorial, for me then, had suggested actively being creatively and "caringly" collaborative. I chose to adopt this standpoint when preparing for my literature review, being open to considering alternative approaches to co-curating in health contexts, and open to developing my ideas from others about the practices that may be involved (Farnsworth & Lovell, 2020, George, 2015, Chong Cuy, 2013, Roelstraete, 2013).

The next step was to underpin these inspirational learnings, thoughts, and ideas with any evidence that may be available within an appropriate literature base. Having embarked on my health sciences PhD, that involved initially scoping the health sciences literature relating to co-curating within healthcare settings and formulating an emerging perception of co-curating within my cancer hospital that could be researched (Grant & Booth, 2009).

My aim was to adhere to the principles of a scoping-type review as a strategy for this, which would include deciding what it was I had intended searching for, identifying potentially relevant studies, selecting, and reviewing these, and then reporting the results (Arksey & O'Malley, 2005). Again, it was hoped that the literature initially scoped in this way could inform the design of my own co-curatorial exploration (Grant & Booth, 2009).

2.3 Reviewing strategy and process

My initial scoping-type review of available health sciences literature was formulated to identify potentially relevant studies from which a selection could then be reviewed and reported upon in a rigorous, transparent, and reflexive way (after Arksey & O'Malley, 2005). My rationale for scoping the literature at that time was to help me broadly discover *what is known from the existing literature about others' explorations of curating as a health intervention*?

Having next developed a combination of focused (though not strictly limited) search terms around curating as a creative health intervention, I'd then set out to identify, as comprehensively as possible, relevant studies from the databases available to me as an NHS employee and university student. As per the detail in Appendix A, three database searches (HDAS, University of Southampton DelphiS, and JSTOR) were carried out using loose and iterative search terms related to containing "curator", "curating", "curatorial", "exhibition", "hospital" and "cancer" in the title. These searches focused on academic journals from 1957 onwards.

There were some issues with these initial terms used, which may have reflected the intended breadth of my search approach. My searches for "curat*" had included over thirty thousand studies, however many articles were concerned with "curative" studies and "melanoma curatopes". My searches focused on "curating" included many articles about a "curation vocabulary" taxonomy for sorting research data (named DPCVocab). Searches focused on "curator" also revealed this was as a concept translated from some Nordic academic journals into English where the translated term can refer to careers' officers, social workers, and teachers.

The databases were then searched again, this time with "exhibition*" in the title or abstract. Again, this second search included many articles (over eight thousand) however a high proportion of these referred to "exhibitionism" within mental health contexts, and older reviews of "Exhibition of Specimens/Patients/Cases" by medical societies that used the phrase in relation to pathology. The DelphiS and JSTOR searches offered around one hundred and fifty articles, though again these were not relevant toco-curating and exhibition-making within healthcare.

Following these library database searches, a combination of my agreed study title was then entered into Google Scholar, a step that I'd hoped might have combined the recommended stages of considering wider journals and knowledge networks (Arksey & O'Malley, 2005). This final scoping review stage revealed several hundred articles including some of from non-health science contexts.

To be selected for initial consideration, articles needed to adopt some form of curating or exhibition-making, with one or more health service user stakeholder groups, as primary data. This aspect was assessed by my reading titles and abstracts of the potentially relevant articles and applying criteria I had devised as my familiarity with the literature had developed. Studies of all designs, and theoretical or discussion articles pertinent to the search query, were considered.

Of the sixteen articles I considered eligible for full-text screening, eleven were contextually disregarded as I had found them on reading to be specific to a museum or gallery setting, without a health focus, or focused on those with a lived experience of an illness (rather than on curating exhibitions about that experience). Articles that concentrated on a diagnosed mental health condition were considered, where relevant, however art therapist explorations with a focus on one individual receiving on referral psychological support were excluded.

Whereas I had tried to better understand the studies I'd selected in terms of curatorial intervention/methods, participation/facilitation, and the relevance of their findings (See Appendix A) it was decided that a formal quality assessment of the articles using a validated tool would not be carried out. This decision was acceptable for a scoping review addressing a broad topic where differing study designs might have been applicable (Arskey & O'Malley, 2005).

Due to the variation in study designs I had found on full-text screening, and as the reader will see, my reviewing and interpreting process then took on a narrative feature, with me attempting to chart and arrange the studies "stories" into this one account (Barnett-Page & Thomas, 2009). The following four articles were included in my account as each told me a pertinent story about exploring curating as a health intervention.

A first article, by Moss & O'Neill (2019), explored The Role of the Curator in Hospitals and encouragingly acknowledged hospital co-curating as a specialist role that may bring benefits to hospital life. Moss and O'Neill had elicited from the hospital curators interviewed that their interventions are separate from art therapy, for the reasons outlined above. Moss and O'Neill's aim in this article was to explore the gaps identified when seeking to build and define the role of the hospital curator previously, and from others' explorations (Aston, 2009, MacNaughton, 2007). By including what aspects of their interviewee's role enables curating to impact patients' hospital experiences, their overarching research question was *what is the role of the modern curator in hospital*?

Following interviews with ten curators in hospitals across five countries and three continents, five themes were identified by Moss and O'Neill. These included themes around patients' influence on the outcome of curating, finding that influential involvement tended to be later in the activities, rather than whilst developing them. They also found that patients were invited to reflect upon the components of activities through formal, textual feedback mechanisms, rather than in visual ways.

Moss & O'Neill discussed the potential for the hospital curator to contribute to formal research. However, when analysing the role of the curator in hospital through the interviews, identifying as a researcher did not appear to feature. This lack of an identity as a researcher, by the hospital curators, occurred despite indicating that those involved believed they had seen evidence for what have since been termed the *benefits* of creative health interventions (Sajnani & Fietje, 2023).

Moss and O'Neill also recognised that previous inquiry into the subject stated that one aim of hospital curating may be to create a sense of "quality care", but they did not delve any deeper into this statement. The article's authors felt that hospital curators clearly articulated their aims, and that this articulation included formally involving hospital patients in programme planning and exhibition designing.

Comparisons and contrasts between hospital curating, and curating in gallery and museum spaces, continued in the second article reviewed. That second article was authored by Bryce (2014) and concerned with community arts exhibitions as a form of group knowledge production UK, with the curating activity being supportive. Through explicitly exploring community art exhibitions as sites of knowledge production around mental health, Bryce had identified potential benefits for those involved, whether exhibiting or interacting with the exhibition.

Rather than purposefully selecting a group of patients, Bryce's curating had involved an informal group of service users and staff with an interest in such activity. The activity had utilised socially engaged exhibition design methods to improve understanding about the group perceived nuanced aspects of their health experience such as "strength" or "softness" (Bryce, 2014 p64), rather than perceive a medical diagnosis such as schizophrenia. By using these methods, Bryce had asserted, a new creative and cultural identity had been achieved. Although too loosely designed to count as formal research, this paper about community arts exhibition curating as a form of group knowledge production, had understood the process as a potential opportunity to creatively explore the health (or indeed illness) experience.

The third article I'd identified (Sarginson, 2005) told the story of curating a hospice arts and crafts exhibition in the UK. The article had stated early on that it was not intended that the exhibition should be a research project. The article author had said that they became clear that, to learn more about arts interventions within a hospice environment, the activity would need to have been appraised in some way.

In endeavouring to generate a better understanding of art interventions in palliative care, Sarginson had gone on to provide a historical perspective on making and curating that involved hospice patients, staff, and relatives. The article had described how, through qualitative investigation, the activity had elicited nuanced themes around the experience of illness for the hospice stakeholders. Importantly, I felt, it had advocated the value of curating for improving both the patient and staff experience and suggested that creatively and collaboratively curating exhibitions may have been a creatively engaging adjunct to treatment.

Examples from Sarginson's article included the impact of exhibitions on people's physical health behaviours, and the author had provided vignettes on the impact of the activity on the psycho-social behaviours of those taking part. Sarginson's article had also provided insight into the effect of the curating on other stakeholders. Others taking part had commented on how many more people they had come to meet through the project, suggesting a role for the activity to improve working relationships. Overall, Sarginson's curating of a hospice arts and crafts exhibition in the UK provided an impetus for richer inquiry into the field.

The fourth and final article from my initial review had blended both art as therapy and hospital art curating approaches to explore something the article's author termed psychosocial curating (Bartlett, 2019). Blending creative practices in this way had been, the article suggested, an approach informed by psycho-social studies and psychoanalysis, where exhibitions were considered supportive structures that enabled a spectrum of affects and emotions to be "encountered".

The psychosocial curating article aimed to produce a more rigorous account of the way engaging with exhibitions may have instigated perspectival shifts for both those co-curating and their audience. Bartlett had, however, focused on audience social impact rather than on the affect for those with whom the exhibition was co-curated. This again suggested possible lines of further inquiry into the wider impact of co-curating on the health experiences of those taking part.

2.4 Considering the literature

These four collated articles suggested to me, then, that there may have been multiple approaches to employing curating interventions for understanding and improving the experiences of those receiving hospital care. It was not explicitly stated within the four articles reviewed if they had included people who have cancer. This omission provided another opportunity for my own exploration to contribute, in some novel way, to addressing a gap within the evidence base.

As key studies, these had lacked detailed information about the characteristics of those taking part in the co-curating interventions and of the roles of the interventionists although Moss and O'Neill did provide background to the hospital curators included. That all four articles lacked a clear conceptual definition of curating (or co-curating) was also noteworthy. A recurrent suggestion I had identified throughout was the potential value of co-curating for supporting patients, and those encountering their curating, to have perhaps experienced creative social agency within each institutional setting.

The first article considered, about the role of the curator in hospitals, was perhaps the most relevant to the development of my own planned exploration. Moss and O'Neill had begun considering hospital co-curating as a distinct practice within hospital arts programme management and had considered it in relation to other professional roles in hospitals. Unlike my own planned exploration, importantly I believed, their consideration had not included the co-curating practices as having been specifically supporting or *caring*.

How my reviewing decisions above influenced the evidence I'd scoped, and the considerations I'd then drawn from that evidence, must be acknowledged (Sutton et al, 2019). Although my initial review offered me a good baseline to begin my exploration, searching article reference lists and consulting others about possible search terms, as additional steps, had not taken place (Arksey & O'Malley, 2005). My literature search strategy and process had though perhaps laid the foundation, as scoping reviews can do, for further and more focused engagement with the evidence base.

2.5 Formulating a research question

This chapter began with a review of my hospital based co-curating facilitation practice up to the point of beginning this PhD. That additional review revealed my inspiration and eagerness to explore what was involved in my practice, and a further review provided some contextualisation of hospital curating amidst other curatorial practices.

I then provided insight into how my PhD research idea had developed systematically. I explained how I had conducted my scoping of the available literature to identify and review evidence I'd then reported around curating in healthcare settings. This initial exploration suggested something about how co-curating may positively contribute to the experience of people within healthcare settings but little about the behaviours underpinning those co-curating practices, caring or otherwise. I'd noted that none of the studies reported had been explicitly conducted within a cancer hospital setting.

Due to this identified lack of understanding of curating practices and their related experiences, as could often be the case for arts practices within health contexts (Bleakley, 2015), I had then decided an exploratory research question asking "what?", "how?", "why?" or "in what way?" may be the best formulation to guide my research going forward. The research question I then posed was, "what are the processes and experiences of cancer hospital exhibition co-curating?"

As the reader will see, as my findings were generated, this initial question helped the research expand beyond an exploration of curatorial processes towards a wider theoretical inquiry about the experiences of those processes as "caring". Accordingly, the research question was expanded to accommodate this new thinking (about the quality of these processes and experiences), not just from patient participants' but also from my own and others' points of view. The final guiding research question had become, "what are the processes and experiences of cancer hospital exhibition co-curating as caring?"

Clear objectives were sought for how to answer the question as rigorously as possible. To focus on the interpersonal caring processes and personal experiences of a co-curating project in a cancer care setting, I developed an objective around seeking highly personalised stories (Chang, 2008). That objective would be *to tell stories of a facilitated co-curating project with a group of patients receiving treatment and a hospital audience*. Seeking also, as I was, to focus the exploration by suggesting categorising those stories in a way in which meaning may be negotiated, codified, and presented to others (Williams & Moser, 2019), a second objective involving thematic directionality was developed as *to reflect around and consider any themes of caring associated with the stories from that cancer hospital co-curating project*.

As the reader will also learn, next, elsewhere in healthcare research one approach I'd discovered to investigate and codify the experiences of researchers and research study participants in this personalised way had been autoethnography (Cooper & Lilyea, 2021, Plant et al, 2011). How I adapted and applied highly personalised autoethnographic methods to my exploration is discussed in the next chapter. The remaining chapters of my thesis then go on to explore how that autoethnographic process incorporated my additional exploration of co-curating as caring.

3. Methods

3.1 Introducing my design

This chapter sets out the investigational, analytical, and practical research design deliberations considered in response to my research questions and objectives. It includes detail about the cross-disciplinary approach adapted to creatively resist designation to one reified research approach (Neergard et al, 2009). Designing a research project that crossed arts and health boundaries in this way I had hoped, would contribute to achieving the most *optimal* outcomes (Dougall et al, 2018, Hulks et al 2017, Seale, 2016).

3.2 Focusing this exploration

Focusing on quality and meaning rather than quantity (Watts, 2014), the National Institute for Health and Care Excellence had encouraged qualitative methods in health research (NICE, 2012). Such qualitative methods aimed to address a research question, rather than to achieve an abstract theory, and it was for this reason I chose the qualitative approach for my study (Thorne, Stephens, & Truant, 2016).

Research methodologies have been described as plans of action that shapes one's choice and use of methods, linking them to the desired outcomes (Crotty, 1998). This section establishes how and why my plan of action was informed by and adapted various qualitative research approaches, to better understand the processes and experiences of cancer hospital exhibition co-curating as caring.

Health scientists have agreed that adapted qualitative approaches can successfully explore healthcare experiences (Green & Thorogood, 2004). Nursing researchers had used qualitative research approaches from the social sciences to understand patients' experiences of their nursing practice, with qualitative studies filling an experiential gap that quantitative studies left exposed by lacking patient perspectives (Thorne, 2020). These nursing precedents guided me when designing this co-curating study focusing on exploring both my own viewpoint and those of the potential patient participants.

Within the NHS, acknowledging that patients' perspectives are those best placed to critique and improve that experience had been considered being *person-centred* (NHS England, 2020). Qualitative approaches including interviews, focus groups, and open observations encouraged that person-centredness (Holloway & Todres, 2003). Person-centred qualitative approaches to achieve these included interviews, focus groups, and observations, that captured people's experiences for better understanding.

It had also been suggested that within person-centred qualitative research there was no single correct form of understanding, as *knowledge*, and that multiple viewpoints should be both acknowledged and valued (Anderson, 2006). For this reason, a focus of this research was for me to reflect on multiple experiences of cancer hospital exhibition co-curating being explored, including my own. To achieve this aim, I needed a qualitative research approach that acknowledged my own viewpoint as well as others'.

Before embarking further on exploring the processes and multiple experiences of cancer hospital exhibition co-curating as caring, I needed to again acknowledge my own responsibilities as a creative practitioner and PhD researcher working within the NHS. When undertaking this PhD, “arts in health” had been one label for my field of work, concerned with integrating arts practices into health settings. Also “arts and/in health,” and “creative health” were used to refer to my field, often along with well-being as “arts, health, and wellbeing” and “creative health and wellbeing” (All-Party Parliamentary Group on Arts, Health & Wellbeing (APPG), 2017).

Creativity had been defined as making, producing, or engaging with culture (Arts Council England, 2022, Art Fund, 2017), and at the time of writing, the relationship between creative practices and better health outcomes, or well-being, had also become the focus of recent government policy (Hume & Willis, 2023, The National Centre for Creative Health & the All-Party Parliamentary Group on Arts, Health and Wellbeing, 2023, Warran et al, 2023).

I was aware that the unchallenged inclusion of well-being outcomes within almost all UK arts in health service planning tended to turn away from patients’ experiences of ill-ness by focusing instead on well-ness. This reflected the conceptualisation of health as “a state of complete physical, mental, and social wellbeing, and not merely the absence of disease or infirmity” (WHO, 1948). Wellbeing had often been, and at the time of writing still is, isolated by service providers as an outcome measure for those researching arts in health interventions, for people at all stages of their illness (NCCH & APPG, 2023, APPG, 2017).

I‘d also become aware however that well-being had become an unwieldly concept encompassing psychological states such as of happiness and processes such as approaches to living (APPG, 2017). Characterised by meaningful engagement and efforts to build better interpersonal relations, UK arts in health projects had often (implicitly or explicitly) focused on increasing *eudaimonic* well-being (Lyubormirsky et al, 2011) such as individuals’ meaningful engagement in life and their perceived self-realisation (Wright & Pascoe, 2015). Eudaimonic well-being had been considered a dynamic process rather than an achieved state such as happiness, which was termed *hedonic* well-being (Ryan & Deci, 2001).

The two were not mutually exclusive, I had found, and *flourishing* was often a way to describe a manifestation of optimally combined hedonic and eudaimonic well-being (Stone & Mackie, 2013, Keyes, 2006 & 2002). Accordingly, some UK hospital arts projects had sought to increase flourishing (Sharpe, 2010). Once major problem had come with linking arts in health’s processes directly to well-being or flourishing (Willen et al, 2022, Gordon-Nesbitt & Howarth, 2022, Wright & Pascoe, 2015). Whilst arts in health interventions may have been said to influence well-being, people who were flourishing more may have been more likely to have engaged with an arts in health intervention at the outset (Bone & Fancourt, 2022).

Because of this I had accepted early on that designing this curating in cancer hospital research around any positivistic measure of patient well-being might have been questionable. What is more, I had felt that doing so would have failed to acknowledge the varied illness experiences of people seeking hospital support for cancer (Muls et al, 2022). As a former nurse and having undertaken separate nursing research in this area (Henry et al, 2014), I then decided to actively foreground that my potential study participants, as people with cancer, had contended with their hospital treatment and its side-effects as experiences of *ill-being*, rather than of well-being.

Cancer, I knew, was a disease in which cells in a specific part of the body grow and reproduce uncontrollably, invading and destroying surrounding healthy tissue in ways that cause discomfort and distress (Ferlay et al, 2020). This uncontrollability often meant that cancer treatment primarily focused on treating cancer in a timely manner and responded to the rapid physical change that can occurred as illness progressed. These episodes could be distressing and disruptive to those being treated.

Cancer-specific treatments such as radical surgery, chemotherapy, and radiotherapy, can significantly impact peoples' physical, emotional, and psychological health (Macmillan Cancer Support, 2022, Bultz, 2016, Bours et al, 2016, Grunfeld, 2011, Grinyer, 2007, Coyne, 2007, Woodgate, 2006). That impact manifested as severe pain, fatigue, and depression. Broader existential anxieties faced by people with cancer also impacted their relationships, roles, and identities (Carlson et al, 2012). As cancer has also become, through improved treatments, a chronic illness, and as the number of people living with cancer had risen, the interventions needed to provide support had become more complex (Rodriguez et al, 2020, Henry et al, 2014, Grunfeld, 2011).

Situating the research within this "cancer care" setting, I had aspired to develop a qualitative approach open to considering the full mental, social, and physical, aspects of people's cancer hospital *illness* experience (Fancourt & Finn, 2019). Accordingly, I'd approached the research design acknowledging that this underlying processes of *arts in ill-ness* practices were not yet fully understood, and that my approach needed to be as open to good and bad ill-ness experiences if indeed those were to be improved in some way by taking part.

Again, I'd wanted to consider my own previously stated positionality as *researcher-experience improver* from the outset. Across all diseases, since the millennium, I was aware that methods to improve the illness experience had developed into a formal process called experience-based design (Bate & Robert, 2007a, Cottam & Leadbeater, 2004). Experience-based design had explored how health service providers applied co-design practices to improve experiences of illnesses and hospital services (Sustar et al, 2013). This differed from co-design in arts contexts, which referred to being more creatively hands-on, and working collectively (Culture, Health & Wellbeing Alliance, 2023).

In 2016, The Point of Care Foundation had launched an experience-based co-design toolkit. That toolkit provided a guide for considering patients' experiences of illness using a patient-centred approach called Experience-Based Co-Design (EBCD). EBCD had since been applied by service providers in a variety of hospital settings including in cancer care (Adams et al, 2013, Tsianakas et al, 2012a), where the approach had shown to increase patient engagement (Donetto et al, 2014) and had helped build a sense of agency around the treatment process (Tsianakas et al, 2012b). One preparatory project for this research, described in my personal practice section above, had been part of wider EBCD work.

In my nursing past I had experienced ECBD methods giving visibility and voice to those taking part by capturing and better understanding patient illness experiences of their cancer hospital treatment (Robert, 2013). EBCD components, such as participative workshops with storytelling, had prompted group discussion around aspects of treatment (Point of Care Foundation, 2019, Weston et al, 2018). The workshops had enabled cancer patients to draw understandings from their personal stories and to recognise significant moments that shaped their overall illness experience (Bate & Robert, 2007a). Through reflecting together on these experiences, patients had developed shared narratives of visibility and voice, and ideas for improving the quality of hospital treatment they received (Bate & Robert, 2007b).

Wider EBCD project facilitators – in my case hospital clinicians – had employed the use of storytelling and drew on outside examples of filmed vignettes (Kings Fund, 2011a). Creative or even artful EBCD adaptations had been encouraged (after Point of Care Foundation, 2019) and were seen as important for considering the values and behaviours of the participants involved in service design (Clarke et al, 2017).

Apart from edited film interviews, however, I could not find any examples where other creative media or artworks had been incorporated into cancer hospital EBCD interventions. There may be valid reasons for this, they felt. Typical interventions were completed within a limited timescale set by the hospital's improvement team (Blackwell et al, 2017). Interventionists had also usually been health workers with a clinical focus (such as nurses), which limited the possibility of integrating more in-depth creative components into the EBCD structure.

The lack of creative output also reflected, I felt, a perception that creative methods of investigating cancer hospital service-users experiences were not fully understood by clinical scholars (Warran et al, 2018, Daykin & Joss, 2016). In-depth reviews of any arts-based mechanisms involved were extremely rare (Given, 2008), and it was difficult to isolate the positive effect of any artforms used (such as film) from other factors such as enhanced communication styles and peer support (Bleakley, 2015).

Taking into consideration the above, I sought to integrate my qualitative approach with some artful EBCD adaptations (after Point of Care Foundation, 2019) particularly audio-visual storytelling, and photographing, into the exploration. Tentatively, at least, I wanted to employ premises, procedures, and principles of the arts (Given, 2008). I wanted to inform both the research process and make the research more accessible by doing so (Knowles & Cole, 2007a).

In terms of how to display these illness stories as research, and again with no precedent, I found myself turning to my earlier field of sociology. A practice base discovered by me had been that which manifested in the publication Live Methods by Les Back and Nirmal Puwar (2013). This publication included the chapter (also published separately) Curating Sociology, which set out co-curating as an arts-based social research method for exploring shared experiences.

Creatively collaborating around a curatorial concept, making an art exhibition, and encountering a public audience through the exhibition, Curating Sociology suggested, provided a range of methods available to imaginative social researchers (Back & Puwar, 2012a, Wright-Mills, 1959). Through the arts-based process of creative collaboration, public encounters, and exhibition-making, a co-curating researcher gained differentiated and nuanced viewpoints, it was said (Puwar & Sharma, 2012), as co-curating exhibitions had also gained more widely (O'Neill et al, 2016, Krzys Acord, 2010). Drawing upon curatorial sociology to provide a working definition of hospital curating as research for this thesis, I settled upon defining curating in this context as *involving creative collaborations, exhibitions-making, and public encounters.*

Fun with Cancer Patients, described in the previous chapter, was one example of a sociological arts-based exploration of illness experiences (Lambert, 2016). As the reader will see, one key difference anticipated between Fun with Cancer Patients and my own hospital-based exploration was that the “artists” in my co-curating research, I’d anticipated, would be the potential patient participants. Also, rather than a professional artist being involved in facilitating the exhibition, instead this curatorial role would be to be taken up by myself as trainee researcher. As a co-curating research project, Fun

With Cancer Patients had provided a blueprint for designing my approach to telling the stories of people’s illness experiences. How those stories were to be told will be described next.

3.2.1 Telling the stories

A challenge for me as qualitative researcher was how to best tell what needed to be highly personalised stories (Chang, 2008). Through my research training I had become aware of autoethnography as a way for a researcher to explore a particular phenomenon from multiple perspectives (Murrell, 2011). Considering an adapted autoethnographic design for my qualitative research presented me with an avenue to subjectively explore and knowledge-seek from multiple perspectives, without any postpositivist emphasis on validity, reliability, and objectivity.

As an aggregate of three components - “the self (auto), culture (ethno), and writing (graphy)” (Adams et al, 2015 p54), autoethnography as a healthcare research method had also been associated with notions of “caring” (Hughes & Pennington, 2017). Maintaining both a relational ethic, as caring for others taking part in the research, and an ethic of personal care, were an important consideration of autoethnographic approaches (Cooper & Lilyea, 2021). I had not used autoethnography to explore my experience of nursing previously but was aware that autoethnography had offered others a more creative opportunity to examine the impact of personal and professional behaviours on nurses’ healthcare practice (Peterson, 2014 p227).

My rationale for drawing upon and adapting autoethnography as a qualitative research approach was that, in healthcare research, autoethnographic case studies can provide depth and a sense of realness to a phenomenon that may be difficult to obtain using less subjective approaches of inquiry (Condon et al, 2021). In autoethnography, a researcher was not trying to become an insider in the health setting, but “he or she, in fact, is the insider. The context is his or her own” (Duncan, 2004 p3). To achieve this realness, autoethnography also drew upon more creative research traditions including narrative research, autobiography, ethnography, and arts-based research (Cooper & Lilyea, 2021).

Creative researchers described arts-based autoethnographies as processes that use “the expressive qualities of form to convey meaning” (Barone & Eisner, 2012 p. xii). Visual researchers also deemed autoethnography as potentially more accommodating for explorations of visual data (Mannay, 2016). Creative autoethnographies freely and successfully integrated representational aspects of what was being considered (Cooper & Lilyea, 2021). An adapted visual autoethnographic approach also allowed for an assemblage of data from other qualitative approaches into the health research, including case study (Hughes & Pennington, 2017. Mills, Durepos, & Weibe, 2010).

Assembling autoethnography alongside a case study approach enabled in-depth explorations of complex issues in real-life health settings (Crowe et al, 2011) rather than just surface level queries (Stake, 2005 p443). Three attributes of studying cases, it was argued, were that doing so invited the gathering of rich, detailed data in an authentic setting, and supported the idea that much of what we can know about human behaviour can be best understood as lived experience in a social context, without predetermined hypotheses and goals (Willis, 2007 p240).

However, an essential element of pure case studies according to Ragin (1992), was that they had been *found*. My own centrality as project facilitator in their proposed exploration disqualified this empirical element. The co-curating in this study would not be found by me as the author – it would be generated and considered through my practice. As the co-curating in this study was created, and that co-curating as caring (or otherwise) is a thematic construct that may coalesce through the research from my own positionality as qualitative researcher, this adapted autoethnography could be deemed case specific.

Case specific autoethnography, I'd discovered, could be an approach that benefits from not being highly structured but reliant instead upon the researcher to determine specific procedures (Cooper & Lilyea, 2021). In terms of the autoethnographic case study approach I adapted when designing their exploration, an *instrumental* autoethnographical structure was again felt to be the better fit. This was because, in instrumental autoethnographic case studies, the intention had not been to focus on the individuals involved but on the insight that they had provided (White, 2009).

Ultimately, however, I chose autoethnography as the structure, procedure, or instrumentality of the design, because the onus for "interpreting and applying an autoethnographic text should be – perhaps can only be – supplied by readers" (Banks & Banks, 2000 p233). Accordingly, I intended inviting others' interpretations of how any shared concepts and patterns of meaning-unity were going to be presented within this thesis.

Readers of this autoethnography would be encouraged to feel and to *care* for themselves (Mendez, 2013 p281). This stimulation of readers to care, had offered exciting potential for previous nurse auto ethnographers wishing to connect with a broad audience of readers who may have not otherwise accessed health research (Peterson, 2014). I too chose an adapted autoethnographic approach so that as broad an audience as possible could access, interpret, consider, and *care about* this research.

When visualising such analytics for this study, the word consider was selected by me on the basis that, for most people, "to consider" meant to spend time thinking about a possibility or deciding. Up to this point, it had been suggested that co-curating, as a creative health intervention, has not been fully understood. Selecting the word consider was reflective of the fact that the nature of the intervention, and any role the intervention may have in supporting health, required wider consideration to be better understood.

Figure 2 (below and after Denzin, 2014) was a visualisation of my autoethnographic qualitative approach to experiencing, considering, and understanding the cancer hospital co-curating studied. It encompassed, as we have discussed, looking out to the world being studied, listening to that world, and then bringing the looking and listening back to an audience for their consideration, through this thesis.

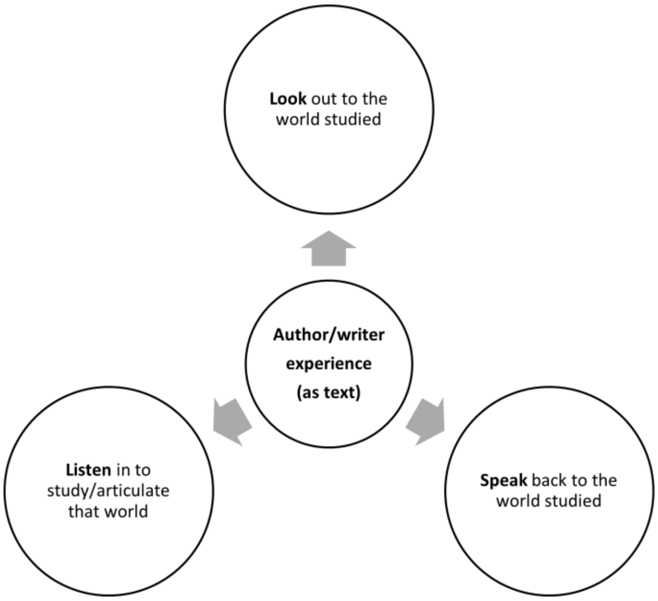


Figure 2 Visualisation of the autoethnographic approach.

How the adapted autoethnography was to be written needed to be decided next. Guidance for this was found through the principles of qualitative description (QD). In previous studies, this method had gathered rich descriptions about phenomena which little may be known about (Bradshaw et al, 2017, Kim et al, 2017, Sullivan-Bolyai et al, 2005), including phenomena associated with healthcare practices (Polit & Beck, 2014).

A QD approach also addressed research questions focused on discovering the who, where, and what, and this sat comfortably with my own questioning the processes and experiences of cancer hospital exhibition co-curating. I sought to explore (and better understand) co-curating as a unique healthcare phenomenon and process, also to explore the perspectives of the people involved in it

(Caelli et al, 2003). Lastly, I had also strived to stay close to the “surface of the data and events” (Sandelowski, 2000 p336), where the phenomenon in question could be described from the perspectives of multiple participants (Sullivan-Bolyai et al, 2005).

Accordingly, a blended approach was designed that adapted autoethnography, drew upon sociology, and integrated elements of patient-centred hospital care design and QD. It was hoped this would be carried out in a way that best described but also analysed and attempted to explore cancer hospital exhibition co-curating. The steps for how that exploration was “crafted” thematically will be described next.

3.2.2 Considering the stories

As mentioned in Chapter 2, a second objective involving thematic directionality for the thesis was to reflect around and consider any themes of caring associated with experiences of my cancer hospital co-curating project. Accordingly, I looked for ways of better understanding the processes and experiences through looking, and listening, telling, and considering the experiential stories in a thematic way.

Means of crafting themes around people's stories, as research, have been varied but similar in intention (Watts, 2014). For my study, a reflective approach to crafting my study data in a way in which meaning could be negotiated, codified, and presented, (Williams & Moser, 2019) would be Schön's.

Donald Alan Schön (1930-1997) had trained as a philosopher, but it was Schön's concern with the development of reflective practice for which I, having been a nurse, was aware. In The Reflective Practitioner (1983) Schön's novel approach suggested knowledge inherent in nursing practice could be understood as "artful doing" (Ibid p143). Schön argued for the importance and possession of practical knowledge as a defining characteristic of professional practice (Newman, 1999). Reflection in real time, according to Schön, had empowered healthcare professionals to develop their practice (1991).

More recently Schön's framework of reflective practice had been developed further, including by Edwards (2017), who endorsed an even more creative approach involving reflection-beyond-action. Encouraging creative outputs such as storytelling (Cheu, 2017), reflection-beyond-action provided new ways of expressing emotion and of articulating any difficulties that occurred in practice (Edwards, 2017, Alden & Durham, 2012, Dreifuerst, 2009).

The decision made to keep a research diary in addition to recording research discussions, as the reader will see, was not only for unlocking the benefits of reflexivity for me as practitioner (Finlay, 2002), but also to assist with my autoethnographic storytelling as a form of reflection-beyond-action. Rather than looking for "infinite reflections" on actions, I felt my approach to considering my research stories was as a "critical practice" that could represent a "practical philosophy" of my actions (Newman, 1999). How this approach came to be applied will be discussed next.

3.3 Developing a study protocol

A study protocol that set out my approach to exploring co-curating in my cancer hospital was labelled "VisualBeats". The VisualBeats protocol was developed at the site (Appendix D), as an embedded study within a wider programme of research. Accordingly, the VisualBeats protocol was subject to a local and a regional, in addition to a university-based, ethical review. As creative health outcomes can often be broad, holistic, and experiential, the study was developed by engaging the multidisciplinary team and study population locally, and these steps will be described next.

3.3.1 Engaging a study population, agreeing the design

England’s NHS long term plan not only encouraged person-centred but also *age-appropriate* approaches to supporting people who were ill (NHS, 2019). Facilitating co-curating as an age-appropriate intervention began before the research by my involving one identified cancer hospital patient population - young adults - in my prior curating projects. At the time of this research, young adults were defined as people aged from their sixteenth up to the day before their twenty fifth birthday (NHS England, 2019).

My research would focus on people within this age range and living with cancer. Occurring during a period of rapid physiological, personal, and psycho-social growth, the illness experience of cancer and its treatment for young adults had been recognised as compounded further due to being at that life stage (Saab, 2022, Ferrari et al, 2021). As a cancer hospital arts programme manager, and formerly a nurse, I was aware that cancer treatment negatively impacted young adults’ sense of self and autonomy, interpersonal and peer relationships, and ability to plan ahead (Sodergren et al, 2017).

Young adults with cancer experienced separation from their families, unfamiliar environments, invasive investigations, and the loss of peer support, during hospital treatment (Bours et al, 2016, CQC, 2016). As mentioned above, although I was unable to locate any literature specific to curating with this patient cohort, I was able to draw upon my preparatory experience alongside other projects, such as Lobel’s Fun with Cancer Patients, to begin engaging and involving the study population.

Involving people who use health services in research and evaluation had been another recommended way of working within the NHS, including with young adults (NHS England, 2020). To involve young adults in the design of this research, I had set up a steering group of clinical leads and young adult patient representatives, at the cancer hospital. An initial VisualBeats protocol design was drafted by me and the steering group over several meetings. This design included my facilitating a co-curating project as both a HAPM and trainee researcher at the cancer hospital in which the co-curating project would take place with a group of young adults there.

The steering group had also agreed a support menu that clarified who else the young adults could turn to with any concerns, recognising the sensitivity and emotional involved in research participation (Naismith, 2019). Due to the vulnerability of these young adult patients, and the potentially emotive nature of the research, four feedback loops were also agreed to protect the potential study participants' welfare. The first was to gain formal multi-level ethical approval for the study, the second to gain informed consent from participants taking part in the study, the third to repeat consent at each data collection point and stage, and the fourth to maintain frequent meetings with the steering group throughout the course of the study (as with the University supervisory team).

A Patient Information Sheet (Appendix E) formed part of the agreed protocol and stated that there may be no clear benefits to taking part in the proposed study, which was named VisualBeats, and which would be made up of a series of facilitated curating workshops and an exhibition. Consideration was given to any feelings of obligation that the patient cohort may have felt towards taking part in the research also (Hope, 2019). The Patient Information Sheet should also outline, the steering group agreed, that a person does not need to have a creative background or experience to have taken part.

Within the VisualBeats workshops, I would encourage the closed group of young adult research participants to agree the most optimal audio, textual and visual material for a hospital exhibition, guided by more familiar examples such as what might be displayed in a social media feed (Thompson & Reilly, 2019). As an adaptation of a focus group, participants would also be invited to consider characteristics of other similarly themed exhibitions through being shown images from these, having any questions answered, and being given encouragement, by me (Fairchild, 2012). Encouraging communication styles had been used to support people with cancer (Ritvo et al, 2017) and to improve communication (Rodenbach et al, 2017). I sought to adopt an encouraging, strength-oriented approach to facilitating the workshops (Zeilig et al, 2019, Mathieson & Stam, 1995).

This facilitation by me of the exhibition-making would also be heavily informed by guidance provided within The Curator's Handbook (George, 2017), underpinned by the principles of Live Methods/Curating Sociology (Puwar & Sharma, 2012) which had inspired me to approach the project *imaginatively* (Wells, 2007) and in the ways discussed earlier.

My facilitation was also to be informed, the steering group had agreed, by the available guidance around creative engagement in healthcare contexts (White, 2009). Those guidelines had advocated responsive facilitation that drew out the creative potential of patients by challenging and motivating them. Flexibility, good listening, and a coaching communication style would encourage creative potential (Ibid), in which spontaneous activities and discussions were given priority (Barrett & Bolt, 2010).

Research participant anonymity was one particularly important topic of discussion for the VisualBeats protocol steering group. Latterly, in Rethinking Research Ethics in the Humanities (2023), Kasstan et al had stated that "It is seldom acknowledged that some participants do not wish to be anonymous, and that enforcing anonymity upon them can disempower them in a way they may see as illegitimate. Researchers should not over-promise anonymity and confidentiality to participants but should instead talk participants through de-personalising processes and the reasons for them." This had mirrored the steering group conversations around any idea of enforced anonymity for those taking part in VisualBeats.

It had been agreed that the young adults would be invited to consent to "my artwork and/or performances being photographed, recorded digitally, audio recorded, or otherwise duplicated for the purpose of publication, public display and exhibition.", through both a research consent form and an additional media consent form, and those procedural steps are also discussed further below). Crucially, participants were also all invited to consent for the *anonymised or otherwise* outcomes of the study to be published or be publishable through the exhibition format, academic journal publications and any other exhibition-related published material.

The agreed VisualBeats research protocol (Appendix D) was submitted for the cancer hospital ethics review (CCR). The hospital ethics review was preceded by a university (ERGO) ethics review and followed by a local NHS ethics review (REC) approval via the IRAS framework. VisualBeats, as extracted from the IRAS application form, was described as *piloting patient-centred curating as a complementary way of researching the experience of a music making programme for young adults hospitalised with cancer* and summarised as exploring how curatorial methods further understanding of the experience for young adults hospitalised with cancer.

VisualBeats, the summary continued, proposed that this understanding could have been enhanced by exploring and communicating public exhibitions co-created by the participants themselves. Aimed at revealing the mechanisms involved in the wider programme of arts participation, the project will include seven co-design groups of 2-6 participants, the exhibitions, and their evaluation, with any impact on the participants and stakeholders being explored qualitatively.

3.3.2 Recruiting to the study

The flowchart below shows the recruitment process for the VisualBeats study (Figure 3 below).

Figure 3 Visualisation of the VisualBeats protocol flow

Taking a purposive sampling approach, the agreed VisualBeats protocol design included recruiting the group of typical young adult patient-participants as key informants (after Quinn-Patton, 2002). Thus, sampling was based on convenience and restricted only by recommendations around optimal focus group sizes, which the co-curating workshops emulated (Ibid). Typical young adults included were those being treated in the cancer hospital, with their illness ranging from diagnosis to end of life care. It was required that participants would be English speaking (to be able to contribute to discussions), available at the time, and willing to take part. Any young adults excluded, it was agreed, would be those considered too unwell (self-reportedly or in consultation with clinical staff), and/or those without the capacity to give full informed consent. The VisualBeats Patient Information Sheet (see Appendix E) clearly stated, as per the steering group and ethics panel discussions that followed, that there may be no clear benefits to taking part and, again, that consideration had been given to any feelings of obligation that the young adults may have felt towards doing so (Hope, 2019).

Following the ethical approvals outlined above and having received confirmation of capacity and capability to commence, young adults eligible to take part in the research were identified from inpatient lists and approached with permission from a support coordinator at the hospital (a member of the steering group and available throughout the project to address any participant concerns). The support coordinator and I had considered that, as a hard-to-reach group that may already have been taking part in other clinical research projects, this patient cohort was one at risk of being over-researched (Clark, 2008). To minimise this risk, the support coordinator identified any other research projects when screening young adults to take part in the research from inpatient lists.

Our special consideration extended to patient being unable to take part in the exhibition without also taking part in the research. As a key feature of the VisualBeats was its explicit *publicness*, inviting young adults to take part with alternate consensual contracts could be problematic, it was felt. To address this, a list of other opportunities to both make art and exhibit art beyond the hospital was made available to support those who did not wish to take part in VisualBeats.

Lastly, it was felt that parental involvement in the research should be a key area of consideration when involving and supporting young adults with cancer. Based on best practice from other prior research projects at the site, it was agreed that parents, guardians, and/or spouses would be welcome at the initial recruitment discussions to support the patient's decision to take part or not. In all, seven young adult patients took part in VisualBeats, and one parent joined a workshop (described below).

The seven young adults consented to join VisualBeats for a minimum of one of seven co-curating workshops. A detailed Participant Information Sheet (PIS) represented the first stage in the informed consent process (See Appendix E for the complete PIS). The purpose of the PIS had been to help the patient participants decide whether they want to take part in the research. The sheet also clarified the boundaries of my research project facilitation role.

The PIS explained the referral pathway in place to a youth support coordinator, and the psychological support services available. The sheet also made clear to patients that any other significant safety issues identified during the research would also be reported in an expedited fashion (none occurred).

All patient participant consenting for recruitment to VisualBeats had taken place face-to-face, following an introductory phone call from me, and sharing of the PIS. The focus of the face-to-face recruitment and consent discussions had been to fully explain and answer any additional questions about the research before the patient participants considered taking part. Patient participant decisions to take part had then been finalised through a consent form that was modified from those usually attached to clinical trials in the cancer hospital (see Appendix F). The consent form was to be taken away by patient participants and a way forward agreed at any follow-up (second) consenting meeting.

The rationale for the enhanced consent approach within the VisualBeats PIS had been my awareness that, although visual research may have been considered as minimal risk, exhibitions containing personal artworks could represent a degree of disruption for some sections of the hospital audience. It had been understood that it may not be possible to carry out publicly engaged visual research, as VisualBeats would be, without risking a degree of psychological discomfort (Lambert, 2018). Visual research involving recorded images of human behaviour may not have been experienced negatively until they were shared within a public domain (Pauwels, 2008).

VisualBeats' consented patient participants were reassured that decisions around personal material that was to be included in the exhibition would be wholly their own and their peers. It was explained that they would not have to provide any personal material to take part in the exhibition as there were other ways they could contribute, such as by agreeing written information that was published, or by discussing technical points about how the material could be displayed.

It had also been acknowledged on the VisualBeats PIS however (and explained further in person) that it may not have been possible to ensure patients' involvement in the project could be anonymised. This would be the case particularly if participants choose to use personal history, diagnosis, or other clinical details, within their contribution to the exhibition. In discussing this I had not wanted to silence a patient participant's creative voice, but rather to set a tone that was appropriate for the complexity of the circumstances (Vick, 2011). Further modifications made to supporting those that took part were around re-consenting before any material was displayed in the exhibition. The potential VisualBeats PPs were assured that a check would be made at each stage of the exhibition co-curating project to ensure they were happy with the level of anonymity being applied.

In all, seven potential patients read the PIS and signed the consent form to show they agreed to take part in VisualBeats. How that co-curating as research was managed will be discussed next.

3.4 Managing the research data

Within the design, three ways had also been agreed to gather and process the VisualBeats co-curatorial stories, as managed research data. For the facilitation story, my observations, as field note data, were gathered by me as a research diary of text and digital images. For the patients' stories, data from the workshops was audio recorded by me as discussion and images. Discussions included loose questioning around participants experiences of the co-curatorial processes. Images from the exhibition that could be considered as participants' experiential data included personalised labels, as well as the co-curated artworks themselves.

Some of these observations and images must, it had been acknowledged, be managed within a public domain (as the artworks were to be displayed publicly). With minimal information about the artists or artworks being offered publicly, the exhibition would be managed simply as a series of artworks operating as "thinking pleasures" (after Roelstraete, 2013), and unrestricted in terms of the materials that could have been employed to create the artwork (Chong Cuy, 2013).

It was expected, however, that whilst such thinking pleasures may have been positive experiences for the audience, they may also function publicly in some critical way (Gaitan, 2013). To manage these eventualities, audience experiences would be captured as spoken feedback, emails received, and social media posts viewed by me during the exhibition period. In the next section, I will set out how the research and its data were analysed.

3.4.1 Observing, recording, and reflecting

My chief task in exploring the processes and experiences of VisualBeats had been to qualitatively describe and then analyse the cancer hospital exhibition co-curating experiences autoethnographically, based on my own direct and subjective observations. As established earlier in this thesis, making such case-specific observations in the field had been a viable method of analysis in social research (Yin, 2013).

For VisualBeats, a highly subjective auto ethnographical approach was selected by me to assist with my analysis because such an approach had encouraged me that, as a health researcher, I could also then take part in *observing myself observing*, something carried out so “that we interrogate what we think and believe, and that we challenge our own assumptions” (Ellis, 2013 p10).

To achieve this, a solicited research diary system for gathering my own observations was developed (Duncan, 2004). There had been many examples of solicited diary use in social research, particularly in health contexts (Jones, 2000). Autoethnographic diaries in health contexts had been considered most appropriate when the author was both an insider (such as a healthcare professional) and an outsider (a researcher), enjoying the perspectives of both (Nakao, 2021).

I had also discovered that diary-keeping had also been embraced elsewhere in relation to curating interventions (Sansi, 2019) and diary keeping methods lent themself to bespoke adaptations (Kenten, 2010). The opportunity to record in both written and photographic form presented another appeal of the solicited research diary method to me as a *visually thinking* author (Bartlett, 2011).

For this research, then, I’d captured my observations and reflections within an electronic diary. The diary included self-observations of internal conflicts, self-reflections around experiences, and perceptions related to the co-curating practice. The diary also captured asides, commentaries, and my in-process thoughts (Emerson et al, 1995). The primary purpose of capturing these diarised internal and external observations was to reflect robustly around the processes and experiences involved in the co-curating practices I was facilitating.

As mentioned earlier, it was Schön’s concern with the development of reflective practice for which I, having been a nurse, was drawing upon in managing my own data in this way. In The Reflective Practitioner (1983) Schön’s novel approach had suggested knowledge inherent in nursing practice could have been understood as “artful doing” (Ibid p143). Schön had also argued for the importance and possession of practical knowledge as a defining characteristic of professional practice (Newman, 1999). Reflection in real time, according to Schön, had empowered healthcare professionals to develop their practice (1991).

Again, Schön's framework of reflective practice had recently been developed further, including by Edwards (2017), who had endorsed an even more creative approach involving *reflection-beyond-action*. Encouraging creative outputs such as storytelling (Cheu, 2017), reflection-beyond-action provided new ways of expressing emotion and of articulating any difficulties that occurred in practice (Edwards, 2017, Alden & Durham, 2012, Dreifuerst, 2009). The decision made to keep a diary was not only for unlocking the benefits of reflexivity for me as practitioner (Finlay, 2002), but also to assist with my autoethnographic storytelling, within this thesis, as a form of reflection-beyond-action.

Ease – in terms of flexibility and accessibility - had also played a part in my decision to develop an electronic diary for my research. Email was easily available as a *bridge* to efficiently collect personal experience for diaries within busy research contexts (after Bartlett & Milligan, 2015), including health settings such as my own (Wolf et al, 2010). Overall, keeping an electronic diary was agreed to be the most optimal way to approach and manage the VisualBeats project – it was above all practical (Vaismoradi et al, 2015). Keeping a diary was also considered the most efficient way to have *scaffolded* any new understanding I may have captured and return it to my practice in real time (Engin, 2011). Reflective diary-keeping offered me "a catalyst for epistemological awareness" (Gerstl-Pepin & Patrizio, 2009 p300).

The diary, finally, had assisted me to remember research events as they were explored, as an aide memoire (Butz & Besio, 2009). Reflections could be managed as stories with critical touchpoints or even incidents (Kinchin & Thumser, 2021), having been managed as memorised observations (Turale, 2020). Diarised memories, I had learned, would be an indication of what had held meaning about the topic explored. They could be confidently drawn upon in autoethnography as significant aspects of my own lived experience (Bochner & Ellis, 2016).

3.4.2 Describing, analysing, visualising

VisualBeats data analysis had involved describing, analysing, and visually exploring the people, processes, places, and experiences, of the hospital co-curating project. It was necessary to devise and agree an approach to this analysis with as transparent an approach as possible. To help with this, I considered the VisualBeats project, and its exhibition, as a unique cultural phenomenon. A key process in the study of phenomena, phenomenology, had been to hear or see what we usually do not, and to not arrive at assumptions (van Manen, 1990b).

My own description and analytic observation of the VisualBeats exhibition, then, would be through a phenomenological “sort and sift” approach to the managing my response to the displays. The foundation of the sort and sift approach was informed by core principles of four qualitative traditions including phenomenology, and case study (Maietta et al, 2021). Consistent with phenomenology, the goal of my adapted sort and sift approach would to be “profoundly present” when encountering the displays almost as new, and to slow down “in order to open up.” (Ibid p2048).

In describing what has been observed, auto ethnographers had often strived for verisimilitude and truthfulness, rather than exactness and accuracy (Ettorre, 2005). It had been suggested that effective autoethnographies could include details alongside feelings and memories (Bochner, 2000). Doing so demonstrated the emotional credibility and vulnerability of the autoethnographer, provided a moving account, and indicated an ethical concern for how others in the story are portrayed.

For this research, I’d intended to describe the VisualBeats phenomenon in a way that immersed readers in a sensory modality and took them through the situations I’d described (van Maanen, 1988). The intention of my phenomenologically inspired autoethnography was to invite that reading the account could be a “vivid, visceral” journey (Stanley, 2015 p148) whilst also being transparently subjective in nature (Ellis et al, 2011). A key function of my subjective account would be to provide enough information for others to deny, confirm, or perhaps triangulate their own thoughts about the phenomena observed (Duncan, 2004).

Accordingly, adopting a phenomenological interpretive stance was an extra step I had taken to manage and interpret some of my subjective observations of VisualBeats. This was not unusual within reflective health research projects (2018). My experiential “interpretation” could be conceived as “interwoven” with the phenomenon described, analysed, and/or visualised (Rodriguez & Smith, 2018 p98), where it was felt to be appropriate.

Another tool from the auto ethnographer’s collection I’d taken advantage of for this research was the ability to extend this interpretive stance towards photographs and other artifacts that may be pertinent to it (Cooper & Lilyea, 2021). Photographs, for example, had invited readers of autoethnographies to journey into relatable capsules of times and space from their own lives (Khan, 2022). I'd found that other forms of data such as still and moving images, of music and sound, also improved the auto ethnographical journey (Haseman, 2010). Harper (2012) had suggested that incorporating visualisations into autoethnographic research recognised the salient role of the visual in people's meaning-making processes. Visualisations had also increased the potential to evoke emphatic understanding of the ways in which other people experienced their worlds (Mannay, 2016).

Accordingly, and again, these features had been selected as ways for managing my reflexivity and for my learning to take place (Pink et al, 2011). It worked in two ways for the VisualBeats project. I had interpreted phenomena as both visual data, such as through photographs in my diary, and I have re-represented their interpretations as visualisations such as by creating diagrams from the stories explored within this thesis.

3.4.3 Coding and theming

The question then was what to do with all this data. It had been proposed that stories alone, as descriptive accounts, could be shared as a basis for understanding health experiences in new ways, such as in nursing (Chan, 2005). Indeed, for this thesis, I had adopted the blend of descriptive-realistic and analytical-interpretive account writing, using literary tools alongside direct quotations and explanations, and some audio-visual data, as described above (Reilly, 2013, Chang, 2008). How these explorations could be further considered in terms of any broader context of caring, also needed to be considered.

As introduced earlier, a highly reflective approach to crafting themes had been selected as a further qualitative step to robustly consider, negotiate, codify, and present my data (Williams & Moser, 2019). The initial approach taken to achieve this was to analyse the transcripts and visual data in a top-down and extractive way.

I was aware that applying thematic analysis without some degree of guidance may not have produced the “masterpiece” they had desired (Watts, 2014 p2). In keeping with the overall spirit of the research, analytic approaches were sought that could be applied creatively, but with some guidance. Reflexive thematic analysis (RTA) was one approach that provided me with clear reflective steps to follow and had been successfully applied elsewhere within multi-disciplinary research, were those inexperienced in qualitative analysis needed to obtain a holistic, descriptive overview of a data set.

I’d found it to be true that developing the necessary skills for thematic analysis took some time (Watts, 2014). Although thematic analysis felt initially a straightforward process to grasp, it rapidly became confusing for me, again an experience common to other early career researchers (Braun & Clarke, 2012). To support this next step in managing the study, a short course on thematic analysis was completed at the University.

Two further compelling features of thematic analysis for this research, into which little is known, were that theme development could be provisional and tentative, with no requirement to generate an ideal number of themes. Also, it was understood from the RTA guidance that an answer to the research question need not necessarily be found at the analytic stage of a study (Braun & Clarke, 2021), which opened further reflective possibilities for me as a trainee qualitative researcher.

A singular goal of my RTA-derived theming for this study had been to ensure each theme generated had a central organising concept (Braun et al, 2014). For theming textual data from the workshop accounts, transcripts were split between discussion generated by me and that which was generated by the patient participants. Mindful that measuring the frequency of distinct thematic categories should not have been considered a proxy for significance (Vaismoradi et al, 2015), the transcripts were also approached in the view that interpretations should have been presented with sufficient quality and meaning, rather than with sufficient quantity (Watts, 2014).

Semantic codes were to be inductively used to identify any explicit and surface meanings of the data before latent codes deductively used to refine underlying ideas, patterns, and assumptions (see Figure 4 below). Latent coding required a more interpretative and conceptual orientation to the data, which in my case meant thinking about my earlier reviews of personal practice, experiences of cancer hospital curating, and the literature (Braun, Clarke & Rance, 2014). That said, I made a conscious effort to avoid arriving at positivistic and discovery-oriented decisions when developing codes, and the themes that followed.

This pragmatic approach to RTA had been applied to both textual and visual data. Where themes did successfully become generated, the structure chosen for the presentation of those themes was to do so in an exemplificative way, declaring the essential nature of each theme and then presenting exemplars. The rationale for doing this had been for me to demonstrate to the reader the nature of each theme as an essential experience of the phenomenon being experienced (van Manen, 1990a).

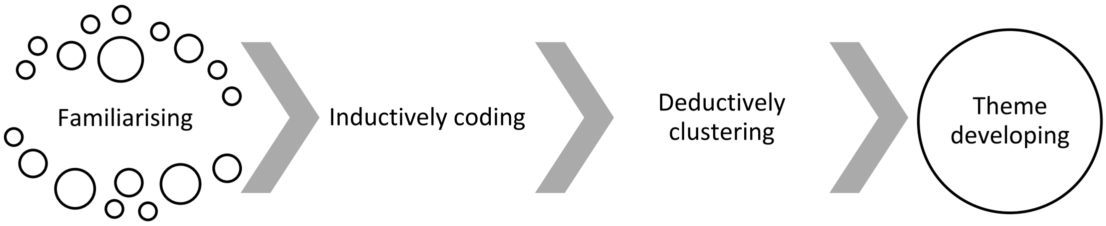


Figure 4 Visualisation of the theming process

For this research, “theming” as a separate concept from the arts, had offered an interesting extra consideration. Within arts contexts, overarching exhibition “themes” had been defined as those that invite audiences to make connections when looking at displays of artwork (Puwar & Sharma, 2012). In What Makes A Great Exhibition, Marincola described such exhibition themes as “echoes within the progression of works on display, so that each new artwork we encounter informs our understanding of the one we just saw as well as the one we see next” (2015 p11).

Although perhaps different in the health and social sciences, the idea of a theme representing a connected concept or echoed story had helped me to be creative with my approach to analysing the displays in phenomenological terms. Within phenomenology, exhibitions and their themes understood a culture in such a way that the members of that culture were aware of *collectivity*, made visible by the works of art functioning together. If themed successfully, I felt that the artworks would reveal *a connected truth* about a community, creating a *dwelling space* in which an echo of perceptions might characterise a group, society, or culture (after Tonner, 2018).

In this thesis then, as in my pragmatic understanding of thematic analyses and curatorial themed spaces, a viable theme would be one considered *a shared concept and pattern of meaning-unity*. Meanings given to the themes would be objectively and collectively constructed rather than discovered by me alone. My analysis happened in real-time throughout the course of the research, with the textual and visual themes generated from the dataset as it was gathered. and, without hoping to reveal any singular *truth*.

The PPs' spoken workshop contributions, as a set of data from which stories could be crafted, were first encountered by me through workshop facilitation, then through transcribing the recorded discussions. Transcription began with the first workshop and continued throughout the VisualBeats project.

Having typed and printed the word-processed transcriptions, I had initially manually reviewed the PP's contributions as multiple read throughs. I'd accessed a specialised qualitative analysis software (NVivo) to assist with analysis more efficiently, but soon found that the software had posed a technological barrier and an extra step away from the data, which was unhelpful.

When transcribing, and when reading the transcripts, my early reflections had been captured within the margins (penned) and in my diary (word processed). A conscious effort had been made to reflect on any non-verbal cues I'd picked up during the workshops. Any non-verbal communication, where it was picked up, had also been considered where captured in my diary.

Any early assumptions made during my familiarisation with the PP's transcripts had been member checked in real time with the PP's during the remaining workshops, where possible, and later reflected upon in the research diary. Also, transcriptions from past workshops had been used by me to generate discussion in later workshops, eliciting the PPs reflections on their experience as part of the analysis, and had been considered a guide to direct attention during the remainder of my analytic process (after Locock et al, 2019).

Whereas the familiarisation with the PP's transcripts had been engaged, the next steps I'd then taken were intended to also be systematic. Following familiarisation with the data, my analysis of PP's workshop transcripts had included inductively coding and then deductively clustering what had been transcribed. Initial inductive coding had been iterative, with early codes reviewed against my recordings. This followed best practice for ensuring data relevance and distinctiveness (after Watts, 2014). Coding data in this back-and-forth way was initially intended to capture ideas that I was forming and, as was the case, had encouraged my re-engagement with the entire transcript.

This early inductive coding was a slow to evolve process for me. As there were no lists from which the initial codes could have been chosen, any early codes generated were based on my prior experiences as a HAPM project facilitator developing my understanding of co-curating practices. Accordingly, this initial coding had been approached by me in a “consciously curious” way (after Trainor & Bundon, 2021 p9), returning often to the research question, aims and objectives.

A codebook approach, though acknowledged as not essential, was employed by me initially to consider, and collate the patterns of PP discussion topics that made up the initial inductive codes (Maietta et al, 2021). In keeping with a loose and evolving approach to this first step of thematic analysis, transcription content had then been assigned to more than one of these initial codes.

A second step of deductive code refining was conducted, again as recommended, to ensure I’d generated a more reflexive analysis (Braun and Clarke, 2021). To refine the codes deductively, they were clustered together and considered in terms of their similarities and differences. The curatorial processes of creative collaboration, publicness, and exhibiting were employed as deductive framework to assist with this (after Puwar & Sharma, 2012). I had hoped that this more deductive approach may have been more helpful, at that stage.

The newly clustered code data were then grouped into one document for each, for thorough review. That review had considered if each developing theme had a clear enough boundary, and if there had been enough meaningful data available to evidence each theme. This initial review had also considered how diverse the data in each theme was, and if each theme had conveyed something that was felt to be *important* (after Braun & Clarke, 2021).

As each cluster was reviewed, a PP quote had been assigned to each developing candidate theme to ensure a matched core meaning. I had understood that the frequency of quotes being assigned was not necessarily an indicator of the significance of a candidate theme. Instead, I’d sought that a theme should be a shared idea meaning or concept, a pattern of meaning-unity that shows conceptual coherence (Braun & Clarke, 2021).

Analysing my own hospital exhibition co-curating facilitation as a thematic dataset had meant considering two sources: the style of my workshop conversation contributions (as external observations), and my reflective diary entries of facilitation (as internal observations and images). Again, the seven workshops had been audio recorded, and my workshop contributions reflected upon when transcribing the recorded discussions. Transcription had begun soon after the first workshop and had continued throughout the weeks the followed. Reflection-on-action emanated from revisiting the workshop data and reflecting *around* the researchers' conversational style (after Schön, 1983/1991).

The first analytic step taken had been to look for any application and/or adaptation of my prior facilitation styles to the co-curating context (Edwards, 2017). Bringing my prior coaching experience involving flexibility, listening, and effective communication had been intentional. Adopting active listening and applying gently challenging and motivating language had, it was hoped, encouraged the participation of the PPs (after White, 2009).

Having typed and printed the word-processed diary, again I had initially reviewed the data manually, as multiple read throughs. When re-reading the diary, my early reflections were captured within the margins (written in pen). Any early assumptions made during this re-familiarisation were then analysed in relation to Donald Schön's framework of professional reflection (1991). Schön's framework was selected at that stage, and as discussed earlier, to best reflect on what is involved in the technique (or "art") of facilitating the co-curating (Schön, 1983 p18).

I had then analysed entries semantically and inductively, being mindful not to over reflect. Again, the main goal of reflection and thematic analysis had been to ensure a central organising concept (after Braun, Clarke & Rance, 2014). Diary data were then clustered into refined codes by me alone, and from which candidate themes had then been developed, accepting that my preconceptions may have influenced a process that was consciously monitored for time given to complete. This was because critiques of Schön's framework had been that its application could collapse into a logical "abyss of an infinite regress" involving ongoing refection upon reflections (Gilroy, 1993).

The results as findings generated from this thematic process will be discussed below. First, I will take the reader through a significant adjustment required to manage the co-curating as research during an unexpected global pandemic.

3.4.4 Adjusting (to COVID-19)

The ability to adjust projects in the face of unexpected challenges had been an expectation of trainee researchers. COVID-19 was a contagious disease caused by the virus SARS-CoV-2 and declared a pandemic by the World Health Organization on March 11th, 2020. Taking place as it was at this time, the VisualBeats protocol had then to be adjusted as a response to challenges presented by COVID-19.

The exhibition planning section of the research was that which was getting underway when the UK social lockdowns were being instigated to reduce disease spread and prevent health services from becoming overwhelmed. The movement of people in my health setting was heavily restricted.

Being aware of early evidence suggesting that social distress caused by the COVID-19 pandemic may have impacted on cancer progression, and that people with cancer may have experienced heightened psychological burden at the time, I had proceeded with caution. Within the hospital where VisualBeats took place most research activities had closed to new recruitment. Outside the hospital, the research methods community were actively seeking and offering solutions in order to continue appropriately. The adjustments I had made in response to the unforeseen challenges of the pandemic drew on these solutions.

As the VisualBeats protocol had involved contact through fieldwork, adjustments were sought to safely navigate the constraints which the lockdown and social distancing had entailed. A useful source of information I had found for completing fieldwork during COVID-19 was a crowdsourced document initiated and edited by Deborah Lupton (2021). Lupton's document had explored ways for turning fieldwork initially planned as using face-to-face methods to be more hands-off, as was the case with VisualBeats.

Other helpful publications I had found for adjusting VisualBeats appropriately included Kara and Khoo's three Rapid Responses, which explored creative approaches to researching during COVID-19, the ethics around doing so, and had offered new ways to collaborate creatively (2020). Kara and Khoo's other two very useful publications at the time had also focused on care, as well as response, reassessment, and resilience, in relation to adapting research to the new challenges COVID-19 brought (Ibid).

Of interest in relation to my research question, Volume II: Care and Resilience had discussed how others responded creatively to the challenge of researching amid the COVID-19 pandemic in diverse, thoughtful, and creative ways. Accordingly, my adapting the participatory aspects of the co-curating projects had also included reflecting around researcher–researched relationships and more *mutual* needs for caring. Fostering of caring patient and researcher resilience had been rarely discussed in research methods books previously to that. In the global pandemic, Kara and Khoo had suggested, "anyone may be vulnerable – researcher and research participant alike – and shifts the power balance in research relationships" (2020a and 2020b).

My response, then, had been to seek ways of continuing with VisualBeats safely. After discussing this with the research steering group and University supervisors it was agreed to submit amendments for site, NHS, and university ethical approval to continue. Table 1 below summarises the rapid adjustments made to counter the impact of COVID-19 on the VisualBeats protocol design.

Table 1 Adjustments made to the VisualBeats protocol design in response to COVID-19

March 2020	Evidenced that psycho-social distress caused by the pandemic might have predictive capacity for cancer presentation and progression. Project steering group and university supervisory teams agreed to navigate constraints and continue with the activity.
April 2020	Research design amended accordingly including adopting a blend of digital and non-digital forms of engagement and feedback. Timeline adjusted to include exhibition beginning from month three rather than month five. Ethical approvals re-obtained.
May 2020	Approval to re-start recruitment received following implementation of COVID-19 amendments.

The VisualBeats workshops restarted after a three-month break, I had then also offered workshops alongside the exhibition, to ensure patients were not taking part in the exhibition longer than initially agreed. New ways to maintain communication through the isolation rules, that the COVID-19 lockdowns dictated, were proposed. These amendments, it was hoped, would have been considered "minor" and therefore avoided the significant extra administrative burden of "major" study amendments.

Other participatory arts programmes around the world had responded to the pandemic by developing accessible, appropriate approaches (Kulha et al, 2021), including moving to online rather than face-to-face methods of communication. Accordingly, permission had been sought, and was granted, to conduct the participation in workshops, when they relaunched, by video call.

Without an organisationally agreed system to use, I had chosen to employ Zoom for hosting the VisualBeats workshop video calls. A key influence in that decision was Zoom's ability to have securely recorded and stored the workshop session recordings without interacting with any third-party software (Jenner & Myers, 2019). User-specific authentication, real-time encryption, and the option to backup recordings to online remote server networks had also influenced my decision to use Zoom initially, as the data collected would be sensitive (Zoom Video Communications Inc., 2016).

As the pandemic got underway, it became possible to find evidence that researcher and research participant satisfaction with Zoom maintained its suitability as the only available qualitative data collection tool to have used (Archibald et al, 2019). I was reassured, though, by a rapid review finding videoconferencing to be a useful medium for conducting qualitative research, but cautious of a warning about its potentially negative impact on group rapport (Boland et al, 2022).

Outside of the VisualBeats workshops, COVID-19 had not negatively affected my adapted autoethnographic approach. As the findings below will hopefully illustrate, my heightened sensory experience of the pandemic may instead have led to a more personalised and person-centred approach instead. This enhancement had also been found by other trainee researchers who had reflected around their own personal COVID-19 experience (Khan, 2022).

3.5 Summarising my design

In this chapter, I have provided justification for the VisualBeats protocol design, and for the adapted, blended approach chosen to carry out the project. The chapter has also included a discussion relating to the ethics process for the protocol, how the research subjects were recruited and protected, and how the study progressed.

The chapter ended by explaining the adjustments that had to be made to the research design due to the COVID-19 pandemic. The next three chapters will discuss the exploration of VisualBeats through the 40,000+ words of workshop discussion transcribed 19,000-word diary generated, and 175 images gathered, throughout the project.

4. Findings/Descriptions and visualisations

In this chapter, I briefly describe and visualise the people and roles that participated in the cancer hospital co-curating community studied, the spaces and places of cancer hospital co-curating, then the processes of one cancer hospital co-curating project (VisualBeats). Again, my rationale for providing this step was because such initial descriptions and visualisations may be necessary to begin exploring a phenomenon about which little is known (Bradshaw et al, 2017, Kim et al, 2017, Sullivan-Bolyai et al, 2005).

4.1 People, roles

This first section sets a scene for *who* was involved in the cancer hospital exhibition co-curating. I first visualise then briefly describe the people and roles of the creative collaborators, exhibitions-makers, and encountering publics that, when brought together, make up co-curatorial practice in a cancer hospital. Within the arts, participation had been described as process where the people taking part constituted an artistic medium of their own (Bishop, 2012). If co-curating was characterised as the artistic medium, then, I considered people taking part as patients collaborating and creating as a social group, me as a facilitating HAPM, and as members of the public encountering the exhibition as an audience. This tripartite relationship, visualised in Figure 5 below, will now be explored further.

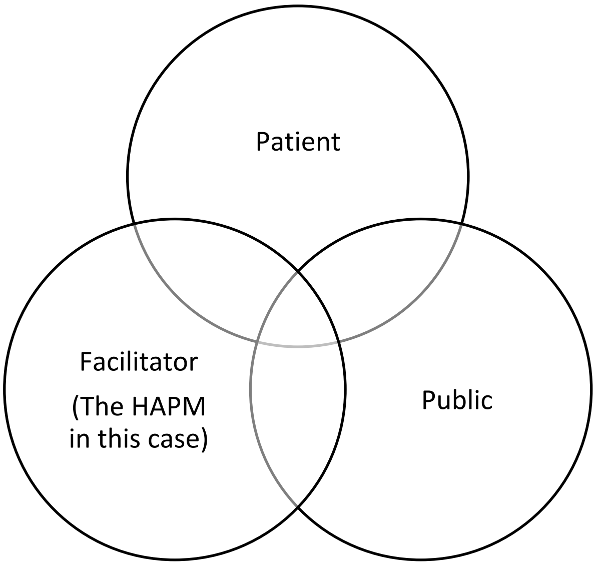


Figure 5 Visualisation of who took part in cancer hospital co-curating (people)

As facilitator for VisualBeats, and as is the case elsewhere in the NHS, I had been a HAPM curating temporary exhibitions like VisualBeats within their portfolio of other performing and visual arts projects. As part of my HAPM role, I routinely invited staff and patients to engage in artworks for temporary exhibitions, which usually took place for three months at a time in spaces set aside for such purposes.

Separately to VisualBeats, I managed the permanent artwork collection within wards, public spaces, and offices, across the two hospital sites. That permanent collection and was made up of four hundred artworks including drawings, paintings, prints, sculptures, and textiles, spread across areas of high footfall but also where people may have been accommodated for days, weeks and even months alone, such as on long-stay wards.

The patient participants (or PPS) young adults with cancer, had been invited by me to take part in VisualBeats as part of their treatment. As per the agreed protocol, discussed in the previous chapter, young adults with any cancer type and at any stage of their treatment had been eligible to take part in this temporary exhibition project.

The hospital visiting public was the potential audience for any temporary exhibition projects. That audience would be drawn from over 60,000 patients that the Royal Marsden treats every year, their friends, family, and the 5,000 staff that work within the hospitals.

4.2 Places, spaces

This second section sets a scene for *where* the cancer hospital exhibition co-curating takes place. I visualise then briefly describe the places of VisualBeats as spaces to creatively collaborate, make exhibitions, and encounter the public.

Often cited as a seminal text when considering exhibition curating in art galleries, John Berger's Ways of Seeing (2008) had challenged me to consider galleries not as "blank" spaces, but instead spaces charged with anticipation. Ulrich Obrist's Ways of Curating (2014) had been similarly ground-breaking in expanding the exhibition concept beyond the "white cube" gallery, into new formats including workshops and discussions. Non-gallery exhibition spaces and places, such as those in hospitals, offered new ways of showing and talking about art (Krzys Acord, 2010, Obrist et al, 2003).

Figure 6 (below) visually represents those descriptions and analyses of where VisualBeats took place.

Figure 6 Visualisation of where the cancer hospital co-curating took place (places/spaces)

The VisualBeats workshops had comprised both physical and virtual spaces. The chief function of these places and spaces, I felt, had been to talk about and show art. The talking had mainly happened through the VisualBeats workshops, though there was some showing of art in the workshops also. Those workshops will be explored in more detail within the following chapter.

Artwork for projects like VisualBeats were displayed in three temporary exhibition spaces. The Royal Marsden's main temporary exhibition space had been within the waiting area of the Sutton hospital's East Wing basement radiotherapy department. This is where the VisualBeats exhibition were to be primarily installed.

Radiotherapy has been a common cancer treatment using radiation. The radiation used was usually produced electrically in the form of x-rays but can also be delivered as electron beams, or by using radiation given off by a radioactive material. Radiotherapy is usually painless to receive. Radiotherapy treatment sessions usually last between half an hour, and an hour. People can have a single treatment or a course of treatments, called fractions, over several weeks.

Patients wait for their fractional treatment in the area in which temporary exhibitions are installed, which has changing rooms should they need to undress and wear a gown (exiting the changing room into a treatment room). Relatives often accompany patients in the waiting area, but not in the treatment room, as radiation may be present.

In the radiotherapy waiting area, temporary exhibition material is installed directly on to the wall or using the hanging rod system set up for this purpose. Floor based artworks had not been allowed, nor had there been equipment to provide sound or media. The waiting area had been open from morning until evening on weekdays and usually busy with visitors.

A secondary exhibition space had been within the hospital’s East Wing ground floor outpatient department blood test waiting room. Testing blood was considered a routine feature of cancer treatment. Most doctors request patients to have blood tests before they were seen. Patients wait in this area on arrival for their blood test, which then takes place in a treatment room nearby. Ninety minutes later, blood test results are available for the doctor to discuss with the patient, in a consulting room. Relatives had often accompanied patients in the waiting area and consulting room, but not in the treatment room, as it was a space where up to seven people can have their blood tests performed by clinical staff simultaneously.

In the blood test waiting room, temporary exhibition material is installed directly on to the wall and using a hanging rod system set up for this purpose. Floor based artworks had not been allowed, but there had been a space for printed patient information and other printed material. There had also been a screen to provide sound or media. The waiting room was open from morning until evening on weekdays and usually busy with visitors.

A tertiary exhibition space had been a corridor within the hospital’s West Wing first floor rapid diagnostic unit. The rapid diagnostic unit provided one-stop new patient assessments for suspected breast, prostate, and skin cancer. A series of tests were performed in the unit’s consulting rooms including diagnostic imaging (mammogram, ultrasound), tissue sampling, and biopsies. Most patients had received their results or a form of diagnosis on the same day as the tests. The unit had also provided family history genetic screening for suspected cancer. Relatives often accompanied patients in the waiting area and in the consulting room.

In the rapid diagnostic unit corridor, temporary exhibition material was installed directly on to the wall or using the hook and line hanging system set up for this purpose. Floor based artworks had not been allowed, nor had there been equipment to provide sound or media. The rapid diagnostic unit was open from morning until evening on weekdays and was usually busy with visitors.

Apart from being installed in the radiotherapy department, blood test waiting room, and rapid diagnostic unit, VisualBeats would also be exhibited in the Royal Marsden’s online space. As in most health settings perhaps, The Royal Marsden’s hospital arts programme operated within institutional framework that prioritised communicating about clinical advances and patient information.

However, the Royal Marsden’s communications team had shown interest in communicating about advances within the arts programme, including about temporary exhibitions. These communications had usually taken the form of one-off posts on social media platforms, designed to engage the online audience with content that was clear, concise, concrete, correct, coherent, complete, and courteous (NHS Elect, 2023). Across all these platforms, content had been accessible to thousands of follower accounts and had encouraged interaction and feedback about hospital services.

4.3 Processes

This section sets a scene for *what* taking part in the cancer hospital exhibition co-curating involved. I visualise then briefly describe the VisualBeats processes as an arts intervention.

Figure 7 (below) summarises the participatory processes visually.

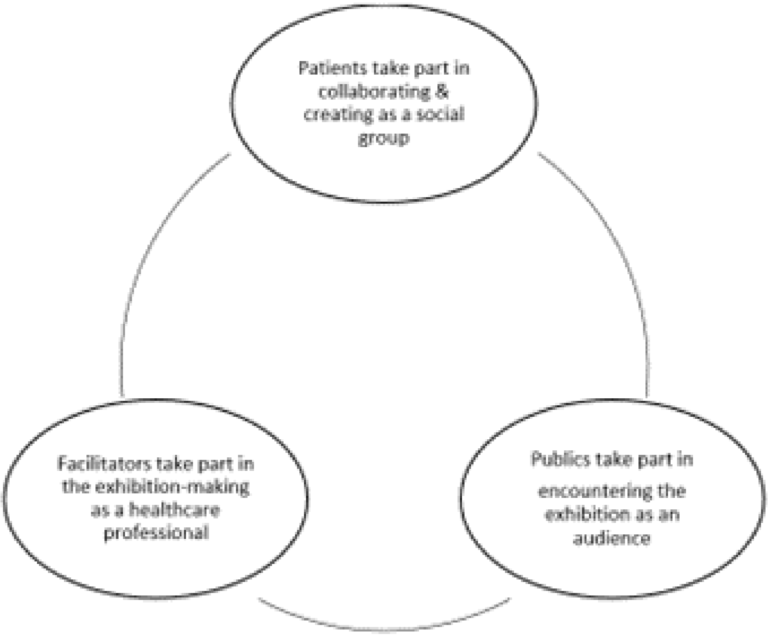


Figure 7 Visualisation of what taking part in co-curating project involved (processes)

Three participatory actions had been involved when taking part in VisualBeats. Firstly, a healthcare professional had taken part by facilitating the exhibition-making. Secondly, a group of patients had taken part by collaborating to create artworks for the VisualBeats exhibition. Thirdly, an audience of the hospital public had taken part by encountering the exhibition both in person and through the online space.

4.4 Summarising the descriptions and visualisations

Together, these brief descriptions and visualisations have shown that projects such as VisualBeats have been a largely tripartite phenomenon. Before exploring this phenomenon further below I will offer my reflections on the complexities of each area of co-curatorial participation found.

Thinking back to my earlier review, these brief descriptions offered similarities to projects that were found in my review of the literature. They had suggested that co-curating may have been contributing in some way to the healthcare experience but offered little about any mechanisms that may have been involved within and between the parties and processes involved.

In terms of people and roles I can summarise that, for the VisualBeats project, these had been made up of an interventionist who was willing and able to lead on the exhibition-making, others who were willing and able to take part in making the exhibition, and more people who were willing and able to take part in viewing and responding to the exhibition. By implying “willingness” and “ability” I am suggesting that some curatorial “techniques” for success may be reflected upon further.

In terms of what the descriptions reveal about the techniques that an interventionist may have needed to apply to ensure VisualBeats’ success, it could be proposed that this was intuitive *know how* knowledge (after McKenna & Slevin, 2008, Rolfe, 1998). Elsewhere in the NHS, programmes of hospital arts projects had been managed by individuals expected to demonstrate specialist knowledge of arts in health work procedures and practices that are underpinned by theoretical knowledge (NHS Employers, 2013).

HAPM-led projects had been described as having an ethereal quality (DeNora & Ansdell, 2014), but the descriptions here suggest one quality may be their *collectivity* (Daykin & Joss, 2016).

In terms of what these descriptions tell us about the unique characteristics of the HAPM role it is this opportunity to engage collaboratively with both patients and the hospital public as an arts audience that most stood out. This affirmation may be of interest to the wider HAPM network who often dwell upon the organisational impact of the role (NPAG Arts, Heritage, and Design in Healthcare Network, 2019).

Up until this point, I had assumed that the “co” from co-curating had referred to collaboration (Krieger, 2001). Another possible signifier for “co-” in co-curating, I reflected, could be to acknowledge VisualBeats as something *complex and experimental in nature*.

Continuing in this vein, the “co” in “co-curating” could also perhaps refer to VisualBeats being *collective*. More so within the arts than within health, the collective had become an activating and affective feature of arts participation (Oprea, 2016). Collectively created arts activities such as shared workshops, events, exhibitions, installations, and/or performances, had often taken on a counter-institutional ethos (O'Neill & Wilson, 2016). Collective curating activities that challenged institutional stereotypes had become a focus of museums and galleries outreach work (Cotterill et al, 2016, Morse et al, 2013). Such challenges, the reader may agree, may have also been a focus of hospital temporary exhibitions like that which has been described here.

Last but by no means least, the author reflected that the "co" in co-curating could also refer to the intervention being consensual, as research. Obtaining informed consent from others included in the narrative presented a common challenge in undertaking this autoethnographic health research (Peterson, 2014). For the VisualBeats adaptation, my process for recruiting and consenting patient participants (PP/PPs) had been extensively discussed and ethically approved. In addition, accessing training in Good Clinical Practice at the Trust, had provided additional guidance to the author regarding information giving and consent-taking.

In terms of what these descriptions tell us about the characteristics of VisualBeats' places and spaces, I'd reflected that, in the museum and gallery sector, online viewing rooms for temporary exhibitions had ranged from simple websites featuring digital images of artwork described with basic details, to highly produced online spaces rich in editorial content (Schneider, 2020). Similarly, the museum and gallery sector used their social media platforms (Facebook, Instagram, Twitter, YouTube) to display temporary exhibitions, though content had rarely reached out to online audiences beyond what had been termed *posting and ghosting* (Ibid). Hospital temporary exhibitions were not operating within such a rich array online spaces.

In terms of processes, these descriptions made me aware that, whilst there had been some recent efforts made to evaluate the impact of temporary exhibitions of artworks (Painting in Hospitals, 2017), most efforts to understand the value of artwork in hospitals had tended to be subsumed within evaluations of healthcare environments more generally (NPAG Arts, Heritage, and Design in Healthcare Network, 2019, DOH, 2007, Arts Council England, 2007/2006).

I reflected that most HAPM's, like myself, had more easily evaluated their hospital's live music programme and performances related to it. It was evidenced that music provision in cancer settings could have enhanced sociality (Iyendo, 2016, Orlova, 2014) and increased patient satisfaction (Bates et al, 2022, Vesel & Dave, 2018, Schmid et al, 2018, Burns et al, 2015, Mackrill et al, 2014). In 1859 Florence had suggested the effect of a variety of colourful objects on sickness had not been appreciated even then (American Association of Colleges of Nursing, 2019), and that still seemed to be the case here.

Overall, the collaborative, creative, participative processes described and visualised here had elicited potential “mechanisms of action” for co-curating (Warran et al, 2022). In the case of VisualBeats this was a tripartite of *co*’s that may be at play within this setting. In the next chapter I transcribe and reflect around the three parties’ experiences of collaborating, facilitating, and encountering VisualBeats to explore any such mechanisms further.

5. Findings/Transcriptions and reflections

As stated earlier, an objective of this research was to describe and analyse, through highly personalised stories, a facilitated hospital co-curating project with patients receiving cancer care. In this chapter, I create an autoethnographically-inspired account of how a group of young adult patients collaborated and created within the VisualBeats workshops, from the recordings and transcriptions of our sessions. Following this, a reflective account is created of how I personally took part in exhibition-making by facilitating the VisualBeats project, from the reflections in my diary. account of how the public had taken part in encountering the VisualBeats exhibition, as an audience, by capturing and examining material from their responses to the displays.

Together, these transcribed accounts were intended to guide the reader through richly narrative, critical, reflections of VisualBeats, *from the inside out* (after Hughes & Pennington, 2017). I create the narrative around discussions that had taken place as part of the VisualBeats workshops, inviting the reader to explore the workshops from their own point of view.

Developed from the qualitative research focus group concept, the seven workshops had taken place over the course of six months (between November 2020 and January 2021) Each workshop had lasted up to one hour and had been held in the evenings, so as not to have clashed with any cancer treatment appointments.

Over the seven workshops, I and the PPs had agreed material for display in an exhibition to be displayed across three separate areas of the hospital between August 2020 and February 2021. VisualBeats exhibition display material would include visual art, written lyrics, sound recordings, and/or video recordings. Individual text labels, displayed verbatim next to the artworks displayed, were also to be developed for each of the PPs taking part in the exhibition, during the workshops.

Led by me, as HAPM and trainee researcher, the VisualBeats workshops had been held online and as blended online and face-to-face sessions following the COVID-19 safety guidance at the time. The online workshops had taken place using secure telephone and video calling software. When face-to-face workshops were permitted, those workshops took place once in an outpatient meeting room at the hospital using a hospital laptop for video calling, and once at a bedside on the young adult inpatient unit using a hospital telephone for the video call.

Sixteen eligible patient participants (PPs) had been identified to take part in VisualBeats workshops by the clinical team. Seven PPs had volunteered and consented to take part, which had meant that the response rate had been 37.5%. The mean PP age was 20.5 years, with the group having been made up of five males and two females. The young adult PPs who had taken part in VisualBeats had been receiving active cancer treatment for a range of disease stages and had represented the culturally and ethnically heterogeneous population of London (UK). Access to the workshops had been inclusive of ability, and one PP who took part had been blind.

PPs had needed only attend one of the seven VisualBeats workshops which were held one per month before, and the rest during, the live exhibition. Each PP had taken part in at least one workshop, with all workshops lasting between 45 and 60 minutes. One PP had declined to attend the workshops after joining the research, due to deterioration of their health status, but had then re-joined later. All PPs from the workshop groups then took part in the exhibition.

The purpose of each VisualBeats workshop had been to discuss how to co-curate an exhibition. As per the protocol, all workshops were semi-structured around the processual guidance from The Curator’s Handbook (George, 2017). Within the workshops, the young adult PPs were also asked about their experiences of taking part in the wider arts programme. I encouraged the group to create and curate material for a VisualBeats exhibition, based on the guidance and their experiences, and to considered others’ feedback to their exhibition.

5.1 Workshop one

(12/8/20 7-8pm, Online)

Designed around The Curator's Handbook (George, 2015), the purpose of the first "Starting Off" workshop was to chat about what putting on an audio-visual exhibition might look like, and to share examples of other exhibitions.

After thanking the patient participants for calling in, I'd explained that this is the first of a series of workshops, the purpose of which is starting off and "to get ready for an exhibition – an art exhibition in the hospital for visitors, your peers, and staff – so in a very public space." I'd remarked that it was hoped the exhibition would go up in about three months' time, and that there would be monthly workshops beforehand. The exhibition, I went on to say, would then be up for three months – until the end of the year. Afterwards, I had mentioned, we would come back together to talk about the feedback we had from the exhibition, and how it went for you as PPs.

"The whole point of the exhibition is to reflect upon yourselves as creative people, and not necessarily as people with cancer" I said, and went on to ask the PPs to, "think more about yourselves as creative people that just happen to be visiting the Marsden for treatment." Next, the creative impetus for the exhibition was explained as being about recent contact with the wider in-hospital music-making activity *VocalBeats*. This project, I'd gone on to explain as part of their workshop introduction, was about "trying to convert some of that experience into a visual art exhibition... creative responses to what you've been experiencing."

I had then summarised their Arts Officer (HAPM) and research role before inviting the PPs to join in the conversation by inviting the others (two PPs and myself in this initial workshop), to say something about themselves ("As much or as little as you want"). The PPs then took turns to introduce themselves. PP1 gave their age (21), talked about their cancer treatment (a bone marrow transplant), their interest in music, and their interaction so far with *VocalBeats.* This interaction included how the activity supports their interest in making beats, saying, "they help me improve that skill really. Every now and again I would jump on the laptop and try some new things."

Next, PP2 introduced themselves and give their age (18). PP2 conveys they have only just started cancer treatment (also a bone marrow transplant) and were currently awaiting early results of the success of that treatment. “I’ve just finished my A levels. I am getting results tomorrow. I’m an artist, er, so yeah, I like painting and stuff” PP2 went on to share. Without prompt from me, PP2 then offered an idea for creative collaboration with PP1 (they had not met before) saying, “maybe creating video of me doing a painting…you could put a track to it or something?). “Oh, yeah that would be cool” PP1 replied.

I then asked if the PPs have any work that they could share today? (“Or would you prefer not to do that?”). PP2 then turned their screen round to accommodate an image of a pencil drawing. “Oh cool. Oh wow!” remarks PP1 in response to the image, to which PP2 replied “That’s sort of my work”. At this point, I recalled a chat during the consenting phase and check with PP2 that it is right they are interested in emotion in their artwork (“is that right?”). PP2 replies “Yeah, yeah, emotion and mental health”.

Switching to PP1, I then asked “what artwork is it that you do? Digital recordings of music? Composing and producing them?” PP1 replied, that “it’s nothing compared to PP2’s talent”, “I’ve only just started, like two months ago. But yeah, especially on the computer I just literally pick instruments, punch them all in and make a beat.” I then mentioned that both are clearly talented and linked this to the point of the workshops, which was to put on a group exhibition together, “like you’ve already started saying to each other *you know what we can actually do together?*”

I then shared images of the hospital exhibition spaces that are available, on their screen. I also then clarified the patients who use the busy spaces, describing the hanging systems that can have been used for temporary exhibitions in the spaces, and where a screen for video will be available in one space. I continued sharing their screen and talking about how this co-curating project had been inspired by an exhibition held two years before in Birmingham.

Noting some trepidation in the PPs response to what they were proposing to share, I had then said “Don’t worry. The title of the exhibition was Fun With Cancer Patients. It was specifically supposed to sound weird. There is probably not a lot of fun going on when you’re having cancer treatment. The idea was to disrupt the way some people thought about young people’s cancer care.” I’d then talked the PPs through the exhibition images, offering to share the link afterwards.

The PPS were then shown, and invited to discuss, the overall Fun With Cancer Patients display rather than any individual artworks. “So, you can see they’ve got some digital work, they have got visual work going on there. In terms of what the people contributed, there was drawings obviously, photography, kind of journaling, and written work. That kind of thing” I’d added.

I had supported descriptions of the images from Fun With Cancer Patients with phrases like, “this is almost like a magazine, almost a social-media type display. You can get restricted in what you can share on social media sometimes in the Marsden, right? The idea is that we give you a space to kind of think how you might want to present yourselves. And you can do that anonymously, or as yourself." I'd then gone on to explain how Fun With Cancer Patients included a chalkboard so that, "the audience, the people that were passing, could write messages. And these messages shared with you afterwards. Just to kind of review the show.," suggesting that that PPs might select something similar, to get feedback on their own exhibition.

After this, I had asked PP1 and PP2 for thoughts on the spaces proposed, and the Fun With Cancer Patients idea. PP2 replied, "I personally love both. If I were to choose a space out of the two, I would prefer the blood test area. Only because I think more people would see that." PP1 agreed with PP2's appraisal. I had replied that was good news, then changed the conversation to one, "where I guess it gets a little bit abstract."

I'd then went on to ask the PPs about their *VocalBeats* experience - what was good and what was not so good about it? How did it satisfy them, or not satisfy them? PP1 replied first, saying that the experience had been "positive" because, "they were up for, like, anything – anything musical. It didn't have to be beatboxing, or on the computer. It could be real instruments. It was whatever you wanted to do. They would make it fun which was really good." "You just enjoy the moments" PP1 said. The only less satisfying experience, PP1 offered, if it could be called that, was that the *VocalBeats* team were not available enough, due to demand when they were on site.

PP2 had experienced *VocalBeats* much less than PP1 but did say that the diversity the musicians had to pick up any song had surprised them. After this point, I had asked, "the magic question" which was "if they (*VocalBeats*) could do anything with you, what would it be?" to which PP1 replied, "a video with the whole time-lapse of like a painting or something?".

A similar question was posed to PP1, who also replied, "I've got sort of two like ideas at the moment. One is PP2's suggestion of, you know, having the video and then having the music behind it, to give it that extra feel. But then also I think with the video itself you could do something with the videography as well, to add something just like the music would. So those two angles – maybe to do something with that."

I then asked, and PP1 replied in the affirmative, if help would have been needed to produce the material. I'd checked with PP2 if they had any experience of producing similar material, to which PP2 replied yes, they had time-lapse experience, but that they are "not that hot on editing or the music side of it, so that is not something I could bring to the table. You could have, beside the video being shown, the actual piece so you can see the process. VisualBeats would cut in, and then the work would cut in, and so on. But on like a wall space, you could do like behind the screen a sign about VisualBeats, and information about them. There could be other music players and stuff. Playing their music – then on the art side the actual piece. So, you can watch the screen of how the piece is being created, and also see the final product."

"That sounds really good" I had responded, before reminding the PPs that there had been about eight weeks between this first workshop and the launch of the exhibition which was planned for the end of the second week in October. I'd then gone on to explore the PPs commitment to creating material from the ideas they had proffered. Resources were offered as solutions, including using any separate *VocalBeats* sessions to continue exploring ideas, and asking myself also for assistance if necessary. I'd mentioned that if the resource required is money, for material or software, which may be something with which they could also help.

I had then clarified that there will be another workshop in mid-September, and invited the PPs to maybe "show a little bit" of their developing ideas then? "What are your thoughts?" I had said. PP1 replied, "Yeah, I think if PP2 gets an idea of what he wants to draw, what piece, just like a quick sketch or something. And just annotate it so I know where the artwork is going, and then I could work alongside *VocalBeats* and try and get the right music for it."

I'd then asked if it would be ok to share their details, by email at this stage, and both PPs agreed. The session began wrapping up, with me declaring "you have come up with some great ideas. Some great starting ideas. Have you got any questions for me about the process of how this works or next steps, or anything you might think, *I'm not quite sure how that is going to work*."

PP2 replied that they had a question, which was "if I were to do like a piece, what sort of topic or subject are you thinking of? I work with portraiture, which is my niche. But what sort of portrait would you like?" "Are you asking me, or in general?" I'd checked to which PP2 replied "Both of you". I'd then replied that they had seen prior artwork when meeting PP2 to talk about the study. "I have an open mind. I do not like to direct artists into what they want to do" I'd offered, before asking PP1 if they had any preferences. "No, I think whatever you feel is right" PP1 replied.

"I think you can talk between yourselves. I will put you in touch, and you can always email me or give me a shout with any questions" I'd continued, before stating the date and time of the next workshop, and offering that "there might be a couple more people here if you have got some work, you can present it and get some feedback early on if it is a video piece? How does that sound?" PPs replied that they were happy with that, and the first workshop ended.

5.2 Workshop two

(16/9/20 7-8pm, Online)

Designed around The Curator's Handbook (George, 2015), the purpose of the second "Being Inspired & Having Ideas" workshop had been to begin discussing ideas for the Exhibition. After thanking the patients for calling in I had chatted informally with one of the participants from the first workshop (PP1) about their new beard, asking if it were something related to the (COVID-19) lockdown ("I wanted to see what it would look like. Sometimes I keep it sometimes I get rid of it" PP1 was saying).

When asking PP3 who had also just joined how they were, PP2 had replied they were tired, and it had been a long day. I'd responded to this, "Yeah, I know it's weird that we meet in the evening but when I was setting up the study, people were saying that if you were on the wards the evenings are the quietest time. Then, people might not have things to do, and there would not be doctors and nurses coming in all the time." The PPs replied positively.

At this point, I had introduced that a moderator was invited to join the group, if they agreed. This was something discussed in both the steering group and supervision and, that whilst not compulsory, may be useful to get feedback on the workshop format. I'd began by saying, "I was speaking to one of the participants from last time and said I think I rushed it a bit. He had said it was quick and a bit vague. So "E" (moderator from the wider research team) is going to join just to make sure I am keeping to time. "E" will not take part. Would you mind?" I had then ascertained from both participants that was ok.

With the moderator having joined and introduced themself, the moderator turned off their camera. I'd then introduced myself again, and asked the PPs to please do the same, starting with PP1 ("It might be good if PP1 you go first because you were in the workshop last month weren't you?"). After a short back and forth about where they may have met, PP1 summarised that, "Yeah, we went out for a dinner and that was part of the youth forum. But yeah, primarily the youth forum is where we know each other." I then talked a bit about the fact there are just two participants (and the moderator) saying "Last time, there was a couple of us, and we did alright" before asking the PPs to say, "a fact about yourself that the other people in the group might not know." PP1 took this opportunity to tell the group about the types of international music they like.

PP3 then conveyed they are a "huge pro wrestling fan. Absolutely huge. And even the backstage stuff like how the matches are made – because we all know it's predetermined. I know exactly how the matches are built.” With encouragement from me, PP3 had gone on, “I’d love to do a backstage role which is where you actually write the backstage stories and the in-ring stories, and you actually create the characters.” “Do you do writing as well?” I had asked PP3, to which they hesitated, “I’m taking some time out to do some graphic design which we’ll talk about later”.

I then shared a fact about myself – that I was an aviation geek. I had compared that geeky interest with their visual art interest, which the group responded to in a fun way. I then went on to invite PP1 to talk about their visual art ideas, which came up in the last workshop, and which they briefly responded positively to but without too much detail.

I’d then continued by saying, “with this project what I am really interested in is this kind of crossover between all the different creative things that you are doing. Not just one specific area. Last time PP1 was talking about collaborating with PP2, and we will talk a bit more about that too. Just to give you some facts about what we are trying to achieve with these sessions, they are once a month in the evening, midweek, and there is going to be one more next month. And then after that, if I can, I would really like us to put an exhibition on of artwork – not necessarily just artwork but audio-visual stuff – in the hospital. I have shown PP1 last week where that will be. It is in the blood test waiting area in Sutton, which I think you might know PP2 right, already?” PP3 responded positively.

“There is a TV screen there that we can use, also there is a rail there for hanging material and artworks and whatever. So, the idea was that the material that we get from these sessions we will put up from, say, mid to the end of October until Christmas. And you can change what goes up, you do not have to just agree on something and then leave it up. We will try and get some feedback from the people that are using the space. That will be patients, your peers, staff, people like that. The idea is to allow you to have a zone to show off your creativity a bit more.”

I had then continued, “you do not have to rely on social media, which is always tricky in hospitals. Yeah, and we’ve kind of hooked the project on the back of the *VocalBeats* programme because although that concentrates very much on music, I wanted to use it as a starter for your thinking. Not necessarily the whole thing, just to get you going. So, it would be great if you could just talk a little bit about your experience so far with the *VocalBeats* programme, even though it might have been a while ago. I know PP1 you talked about it last week, but maybe if you could just tell PP3 what you have done so far. I know that you have been doing some stuff since the last workshop, would that be alright?”

PP1 then went on to describe what they had been creating with the *VocalBeats* musicians, saying “they’re sort of like a coach for you”. I’d then asked if any progress was made on PP1’s ideas from the last workshop session. “I sent him a couple of beats that I had made, just as an example of what I can do. Sort of a template basically. But the problem was that I only have the demo version of the software, so I can't go back and make changes once I have made it a piece" they said. The other group member replied, "I've been there yeah." PP1 went on that they had been speaking with a *VocalBeats* musician about a type of software that is good, and if it was possible to get access to this software. I'd replied that they had been speaking to the *VocalBeats* musician already and had contacted the software producer to try and get access. "That's awesome" PP1 replied.

I then checked if PP3 had any experience of the software to which they replied they had not, "I've definitely heard of it. But I have never used it personally." I'd asked PP1 to elaborate on what they have produced so far, for the exhibition. "There is like two instruments. Whereas, with the actual software you can be a lot more creative. So, um, I will probably go for like a similar type of vibe, a similar type of beat, but I will be able to use more instruments to make it more emotional" PP1 replied. The group then discussed another type of software that is specific to Apple Inc.

Following this software discussion, I'd invited PP3 to talk about their *VocalBeats* experience and said, "I know we had a conversation before this about your interests, which are not necessarily musical, but in terms of creativity". PP3 said that they, "used them to basically to relax and take my mind off things. I just sat down and created a beat on a keyboard or a piano or whatever. And you know, that really did help me."

PP3 went on, "in terms of what I do, I am definitely a visual artist, a graphic artist, graphic designer. I have really got into it I would say, this year. I focus primarily on um automotive artwork. And – you spoke about liveries on planes – I do liveries on race cars. That is what I specialise in. I have been doing it on my laptop for about six or seven months. So, you know, I am pretty good when it comes to graphic design, but I still call myself entry level. In all honesty, I am a little bit nervous that what I create is actually going to be good enough for this exhibition." PP1 replied, "I'm feeling the same. Yeah, I am in the same boat."

I responded to this by saying that they did not want the PPs to think that there was a certain standard required be in the exhibition. "I think it is really about you just doing what you want to do. You know, I am here to kind of help you get it into the state that you want it to be in to put it on display, or to have it on a video or whatever. No-one at any point is going to say that is good enough, or it is not good enough, or judge it in any way. Although obviously yeah, we are going to be asking people that see the exhibition to respond to it, but please don't think there is any kind of standard that you need to meet."

At this point, I had been distracted by a notification that someone new had joined the online group. It was the moderator who had to switch to her mobile phone and apologised for the interruption. “That’s ok I was just making sure we didn’t have an imposter” I had said, and the moderator had replied, “No, I am sorry about that. I will go away again now.” (Moderators notes are available in Appendix G).

I had then returned to the discussion on material for the exhibition, saying “what I really want to do is allow you to play to your strengths, but also to ask for help if you need it.” I’d invited the PPs to share any work in progress, which they did. PP3, after figuring out how to share their screen, displayed their graphic design images. The group had responded positively. “I just started off with literally just that. I drew the car out, all from scratch, interpreting it from the original image. Added the livery, which is all the stickers, the paint splashes, added the cool background” PP3 had said.

I had then asked about the software used, and how it compared to very well-known products. PP3 had replied, “Some things are a lot better; some things are a little bit worse”. I’d asked if the development of the drawings is captured in some way, to which PP3 replied “I have dabbled in terms of creating a GIF where you see it from the very beginning, all the little pieces coming together. So, I could create a time lapse, but I have not really invested loads of time in doing so. At the moment I am still learning just how to do it at the highest level.” They had then talked about social media and how files can deteriorate when compressed for sharing.

With the discussion moving into software used to create images, I had asked PP1 what their experience has been of this, if any. PP1 replied that “I am not very good at creating things. I can have a vision, but I would usually need help from people to execute it, if that makes sense?” I had replied that, “I understand totally. I would love to be able to make music, but I am just not musical enough. Do you know what I mean?” to which the group had also replied positively.

Next, the I’d began discussing plans for the exhibition. “We are talking about six or seven weeks. What do you think you could do either individually or with the help of someone else, for this exhibition? We have a mixture of wall space and access to a video screen.” Noticing PP3 had an interruption to their video I’d asked, “Do you need a break, are you alright?” but whatever the interruption, it had been resolved.

I’d then gone on to ask group members that were present in the first workshop if they had remembered the images shared of the planned exhibition spaces. PP1 had said yes, and I then shared my screen and explained there was a long hanging rail along the top and that, “it looks quite smart if you hang framed artwork from these. And you can put any video element you want or music through the screen, or through speakers, or even headphones.”

I had then shared the images of Fun With Cancer Patients again, whilst saying “you will see here how they used a mixture. You have some hanging artworks, some video, obviously some headphones. I mean, it is difficult in these spaces to have piped music and piped sound because people waiting for blood tests, as you might know, are pretty nervous. Not everyone kind of wants to get involved in that way. So, we have to think about that.”

I then invited the group to think about what might work in the hospital spaces available, including written word (images of which were included in the Fun With Cancer Patients display. “But this was actually in a gallery, in a public gallery space,” I had said, “we do not have the luxury of that. But what we do have is the ability to kind of transform a hospital space in a way, for a time, which is unusual. It is a new thing to do. So, having seen those kinds of pictures, you know it does not have to look like that by any means. But what are your thoughts on what you might want to do for the show? And I suppose PP1 you should bear in mind that you will have the software you need”.

PP3 had replied first, “I think we firstly think of a theme, cos the photos you showed us, they had a theme to them. So, everything that we do hang up or put on the screen sort of links together and looks good together. If we think of a theme and then, use our skills to cater to that,” to which I’d then replied, “Yeah that is a very good point. So, the theme for that show, as you saw, was *fun with cancer patients*. That interested me because, what I wanted to move away from with this, is the idea that it is a show by cancer patients. I am more interested in it being a show by people that just happen to be receiving treatment at the (hospital), but people that are creative in their own right,” I’d continued.

They had said, “That last show was put together by an artist with lots of young people. But really, for this project, I am interested in your being artists really. Rather than anyone else, an artist coming in and treating you as patients that need help. So that is where there is quite a significant difference between the two. I totally take your point about wanting a theme. I think that is something that PP2 had mentioned, that it felt a bit vague.”

I then had started talking about the collaboration between PP1 and PP2, who was not at this workshop. They had not been in contact between the workshops, as did not have one another’s contact information. “I will make sure you get that. If of course he still wants to be involved. As I say, I was not able to get hold of them before this workshop.” I had replied, asking also if ideas had moved along, nonetheless. PP1 replied, “I do not know exactly but I know he does like, what is it called, portrait style. Quite um, Picasso type portraits. I got that vibe.”

“OK. And you are going for some music which is quite emotive right?” I’d asked to which PP1 said “Yeah that’s the plan but I want it to sort of match with the artwork around it”. I then invited PP1 to share any developing music, which PP1 did by saying “So this is what I could do from the demo that I have. This is a more like upbeat one.” The connection did not allow the sound to be heard clearly, so I’d also offered to share the music afterwards by email. All PPs gave their permission for email addresses to be shared, for this to happen, saying “Yeah sure” and “Yeah that’s cool.”

I went on discussing developing work, and the possibility of agreeing a theme, this time including PP3. “Which is why I was thinking down this line of perhaps having the process of your drawing showing, PP3? In a way that keeps its quality because I know that is important to you. What are your thoughts about a theme? I mean do you think the same thing, that there should be a definite theme to the show?” I had asked.

“I can feel my cogs whirring to think up ideas” PP3 had said. “We have got the relatively emotive music, um. I am struggling to pin it down.” To which PP1 had responded “I am not sure! I’m not sure, I’m a bit stuck.”

I then continued, “The title of the project is VisualBeats. And that is because it is related to *VocalBeats*, but obviously because it is not all music, it has the visual element to it. So, whether or not that is far too loose a description for a show. They don’t have to be necessarily the same theme, but as long as there is an element of audio and there is an element of visual, I think that could work. But you might feel that is still not quite focused enough? What do you think?”

PP3 had replied that they had created “vintage logos” in the past but was struggling to visualise how these might be incorporated into the new exhibition. “I’ve definitely done something like that before…but it is tricky without having seen it. That is the thing. If I had seen it then I would know exactly what kind of style, colours to re-create, match, give or take. Uh it is tricky, tricky.” PP3 said.

I had then, sensing that these ideas were taking time and effort to form into something concrete, reassured the group that there was time to develop ideas further, and offered, “if you’re interested in relating what you do to (PP1’s) artwork in some way, maybe a good next step for me would be to make sure that PP1’s alright, that he wants to stay involved, and then get that material shared between you both, and you as well PP1?”.

I’d offered to work on this idea between the workshops, finding resources to help the PPs realise their ideas, if necessary, “like with PP1’s software that we are getting as quickly as possible, if there is a package that you need access to, you just need to let me know, because it’s likely that we will be able to get it for you”. I then offered further material assistance, “like if you want to frame some work, and glaze it, I can get sorted for you. So do not worry about costs and materials and things like that. You just need to ask. Does that make sense?"

The group had responded positively to this offer, with PP3 saying their only expense would be printing their artwork, "But other than that, the actual cost of producing it, the actual artwork, that I can do". I'd then said, "If you feel that you should be reimbursed for your time in creating this work then I am happy to talk about that. If you feel we need to negotiate something around that, then just let me know."

As the PPs digested this offer I'd posed another "magic" question, "if you could do anything for the show… you could wave a magic wand and something would appear in this show, could you both tell me what you think that would be?" PP1 had replied, "I would just make like a really good music piece, just an awesome beat and just, you know, if someone listens to it, it gets them like tapping their foot without realising. Yeah." I'd continued with questioning, "do you think we have already made some positive steps with trying to get this software? Or is there something else that we could be doing?" "100% I think that is a really awesome step" PP1 had replied.

PP3 had then replied, to the same question, "Well the first idea that immediately popped into my mind before coming up with a theme, one thing I'd love to do is – right by the entrance of the hospital with people bustling in and out. Don't know if I would do it pre-covid or currently. But, if I could have that sort of theme where in the background you have got all the people coming in and out, I could maybe do the reception, the background, the sliding doors, the glass, and everything. And then, maybe where the S3 bus is, instead of the S3 bus I would do one of my cars with one of its designs or something like that."

"Just so I'm clear what you mean PP3", I'd gone on, "You mean you wanted to actually put some work in those areas? Or you wanted to do a work, a piece about those areas?" PP3 clarified that they had envisioned a piece of art rendering the entrance of the hospital, "I would literally draw all of that out, even the little patches of grass and the benches". "Almost like you're taking a photo of the front?" PP1 asked to which PP3 had replied "Exactly! And re-creating the scene. That is what I would do. But yeah, I am not quite at that skill level yet."

Responding positively to PP3's idea, I'd replied "When you were talking about it, I was thinking you were saying you would have liked to have had a car in the car park with your design on it!", to which PP3 had replied, "Funny you mention that. That crossed my mind as well!" Thinking more about the idea, PP3 went on, "It would take me ages, because one car takes me maybe three days, with the reflections and everything including interior. But with a parking lot you have got to do multiple, multiple cars. You have got to get the perspective correct. Then you have got to do the actual parking lot itself, to make sure all the textures are correct. I could do it, 100%, but not in eight weeks. No way."

I had pursued this idea, talking about wishing to move from the *magical* to the practical. They talked about what hardware and software PP3 used (Wacom tablet) and then explored how the idea could be realised with the time and resources available.

"How could we start to move towards you reaching that solution? What do you think is a realistic way – or an unrealistic way – of moving towards that?" "To be honest" PP3 said, "the only thing stopping me from doing all of the stuff I just mentioned is skill level. I am just not quite there yet. Even if I were really skilled, I do not know if I could do it in six, seven weeks. It's just a bit beyond my scope at the minute." I'd then offered to help PP3 purchase a new digital pen, but this did not seem to provide the solution required, "maybe, maybe, that would be helpful. But even once I had it, I would have to learn how to use it properly because it is a real learning experience. Learning how to use a pen in place of a mouse. So, it is a bit outside my scope all the stuff I mentioned. But I don't know."

"That's fine" I then had remarked, "park that thought. I know it is your first workshop, so I do not want to make you commit to anything now. I think we have had a good conversation around what might be possible. It would be nice if you – and I can see you nodding I hope that it is true. I think that we could just have a think about it and catch up between now and the next workshop. And I will also try and catch up with PP2 and find out what his commitment is able to be. And then I will let you know. As soon as I know. Does that sound like a reasonable way to wrap this up for this evening?"

The group had agreed, and PP3 added, "My brain is like buzzing with some awesome ideas. Because I am self-taught, I train basically every day. Even within the next couple of weeks I could probably draft something up. It will not be the finished product, but I could definitely draft something up. My brain is working already, so this definitely helped."

Noting the hour ending, I'd then said "Alright that is brilliant, that's great news. We have only got a few minutes left – and I do not want to keep you longer than I said I would. So, was there anything else that you were expecting to talk about this evening that we have not discussed? Are you comfortable with what we have talked about?"

PP1 had asked for clarification about any deadline for creating artworks. "There is no exact deadline" I'd replied, sensing some pressure may have been created inadvertently. "If you are not ready then no-one is going to hold us to it. I was hoping that we might get the show up the week beginning the

19th of October. Because our next workshop like this is the evening of the 13th of October, which is exactly five weeks, the fifth week after this. And I was hoping we might then have our ideas almost finalised for the next week to start putting things up? But I do not want to cause any undue pressure with that, because you know things happen, life takes turns. So, you know, if we have one or two pieces to go up, we can always add to it as the rest of the year goes on. How does that sound?"

"Yeah, that's cool I'm just writing that down now" responded PP3, and "I can work with this" from PP1. I had then thanked the PPs and ended the workshop.

5.3 Workshop three

(13/10/20 7-8pm, In person and online)

Designed around The Curator’s Handbook (George, 2015), the purpose of the third “Turning Ideas into Reality” workshop had been to develop ideas into something that can be exhibited and discuss who would be doing what. I had welcomed the PPs and PP4’s father to the workshop (as PP4 is blind and requested their father’s assistance) and established everyone’s verbal consent for the additional group member and explained that Microsoft Teams was being used, as it was preferred in the hospital. I had first gone on to say that PP1 was not feeling well enough to join this time but did want to be updated afterwards. I then had also said that the music software PP1 had requested, was available to them, and that they were working on material.

As part of the informal introductions, PP2 had offered information about the progress of their treatment, which had been positive of late. I had used this as an opportunity to introduce PP2’s creative practice to the group, saying “if you do not mind why don’t you just introduce yourself to PP4 and tell them a bit about what you have been doing up until now? And then you can get to know each other a little bit better.”

PP2 had talked a bit about their age and location, then said “I do art a lot. I did it for my A level, and I thought, I was asked to do a piece for this VisualBeats project. So, I am working on a piece that is a woman who is like smiling and really, really, happy. I am doing that in pencil and then behind it I am going to write “I beat it.” It is supposed to be like *I beat* my, I want to say condition, or disease. Because it does not represent just one condition or something. It represents like all of them if you know what I mean? It is quite universal. I had a disease called aplastic anaemia which affects your bone marrow. So, I had a bone marrow transplant, and I am three months post-transplant now. And things are looking good!”

I then thanked PP2 and asked PP4 if they would like to follow that on with an introduction about themselves. PP4 agreed, saying “I am 23, 24 next month. So, guess I am classified as an old man now. I have a brain tumour which is pressing on my optic nerves. And, I have had surgery three times last year and the tumours just kept on growing back. I have had chemotherapy this year which has not been successful, and I have just recently gone through radiotherapy. As a result, unfortunately I have lost my sight completely. But I am trying to not let that stop me from doing what I want to do. So, I have been putting together a song-slash-poem with *VocalBeats*. And yeah, it is going well. Part of it I am talking about myself in a sense. But it also, the point of it is I want it to relate to others as well who are going through a lot. The theme of it is, like, being a warrior. All those who are going through a lot and fighting through anything are regarded as warriors. And they need to know how strong they are. So yeah, that is the sort of thing, that is what I'm doing."

The group had responded positively, and I had added "There's a similar kind of sentiment...two very different artforms but similar sentiment" before asking again for the PPs experiences of the *VocalBeats* project. I'd then asked PP4, "what plans have you got with *VocalBeats* on developing your piece going forward?", to which they replied, "Well, my plan is to put it into like a solid poem-song, it's just I want it to be something that makes an impact. And it is like PP2 said – it is not just like a specific disease or related to cancer. It can be anything."

PP4 stated he had been working on a weekly basis to develop this material, especially around "certain themes or things, which I regard, or I connect with, this word or that word. And then kind of mind map it in a sense, they write it down. And then yeah, I produce lyrics, and they get me thinking. In the beginning I may have been writing simpler and they've kind of introduced me more to metaphors and so on. So, making my writing deeper. Yes, it has got my brain ticking definitely, as well."

I'd then asked what PP4 wanted to achieve at the end of their contact with the *VocalBeats* project, and added "What I am trying to do in this session is, because we are three sessions in, is just think about some practical ways that we can put the exhibition together. Not necessarily next week but coming soon."

PP4 had replied, "Um, well if I cannot produce like a song I would definitely like my lyrics written up for those to read. I don't know how we would be able to have it, or if people would have to go up close or anything. Don't want people straining their eyes or anything!" I'd pursued this idea by asking if PP4 might need help to achieve this, and they replied that they will "produce the content then someone else can like write it up and put it together". I'd then asked about the possibility of a musical contribution, to which PP4 had replied that they would also endeavour to produce some music too.

I had then explained to the group that, just before the session when meeting PP4 and his father, I had taken them both to the exhibition space. PP4s father had then explained to PP4 what was there in detail including the formats available such as screens, panels, images, words). "So, if you want something printed out, framed, glazed, or something quite rough hanging there, or even something on screen, it is entirely up to you. And I guess what I am wondering is, who is the best person to help you develop that? Do you see yourself doing it with someone in this kind of setting, or do you see yourself doing that with the *VocalBeats* people?" "Because I've been working with *VocalBeats* I want to continue that" PP4 had replied.

I had then asked PP2 a similar question related to material, "You were kind of working with PP1 on the idea of a stop motion film, with perhaps some music on top. Is that still your thinking or?" P2 had replied, "Yeah, yeah, doing the physical piece so people can see it, but also doing the video along with the music, with PP1 yeah".

I'd clarified if a piece about the physical drawing, with photographs being taken as it progresses, is going to be in the exhibition as well. PP2 had replied that was the plan, but also that they are trying to get some artwork from the school "I am just not sure on the whole covid sort of situation with me picking up any pieces. But I am trying to get a couple of pieces so I can maybe bring up one, so that you can have like a couple of different pieces?" I then replied that "you can have as much or as little as you want. If there is not enough space, we will find space for it. We can spill out of the space that we have got to be honest. Do not feel confined."

To turn the PPs ideas into reality, I went on to discuss the making process further, and what help may have been required with that. I'd asked PP2, "is it your feeling that you want to send the photographs to someone like me to work with iMovie, or is that something you can do? Or do you know someone that can help you?" PP2 had responded that they would like help with the stop motion, saying "I was going to send them over to you".

I'd agreed and offered option for sending the material, checking if PP4 has any experience of this, and may wish to contribute. "I used to love doing video editing and everything. I used to create videos and so on. Yeah, I would love to have edited the video but, I would not want to mess it up! I cannot do what I love to do anymore because of the sight issue. Unless you find other avenues, other ways." "It sounds like you already are in a way looking for ways to keep yourself creative" I'd responded. "Yeah" PP4 remarked.

I had then conveyed they are trying to think if there is anyone else in the group that would be able to help PP2; "I'm not saying I don't want to do it; I'd just rather you collaborate." I'd offered demonstrating how stop motion works in iMovie as a possible solution, saying "I could bring the iPad on one of the Tuesdays you are in (PP2), and you could just have a play with it? If I put all the photos in…." PP2 responds "Alright. Well, I do have an iPad pro myself" and when asked if it has iMovie, "Yeah, I could give it a go. But I do need to play around on it and see what I am doing, if you know what I mean?"

Reiterating the offer of an iPad session, I'd then moved on to discuss the framing of PP2s work. PP2 responds by saying, "The work I am doing now, that woman that I am drawing, that's on paper so that would need framing. And then, the stuff I have got at school are all canvases. Some of them are box canvases, some of them are normal. And some of them are on ply and MDF and stuff. So, I do not know what works best for you with that?" I had urged PP2 not to feel constrained, "I think the best thing to do is just choose what you want in the show and then we will work out a way of getting it in. There is always a way of doing it. Sometimes it is nice to not have everything really uniform, to have a bit of variety. You know what I mean? So, just bring in what interests you and what you want to show off, basically." PP2 responded positively to this.

Next, I'd talked about other parts of the exhibition besides artworks; "the other thing practically we need to think about for the show is how we are going to describe ourselves. So, you know, it would be nice to describe you individually in terms of, not necessarily your treatment – your cancer treatment – it does not have to be around that. Its more about you as a creative person. So, you know, it would be nice to think between now and when the work's ready about how you want to describe yourself in the show. Perhaps a little bit about the inspiration for what you have put in the show. And usually, again, I will get that kind of printed out and looking good to go alongside the show."

"Cool yeah" responded PP4. I'd then checked with PP2, who responded similarly "That sounds good yeah". I did not pursue this idea further for now, as they had noted aloud this time that the session was coming close to its end and said, "You know where I am" if any help was needed between now and the next session." "Was there anything else you guys wanted to talk about tonight?" I'd then added.

PP2 had asked PP4 "What type of genre of music or as, like, poem are you doing?", to which they replied "I guess it's regarded as a, like, rap. There is a lot of emotion to it. There is a lot of emotion to it and… I guess the theme of fighting and going against something. Non-violent, so, yep." "Cool, yeah, sounds good. I can't wait to hear it" responded PP2, to which I'd asked PP4 "you haven't got any examples on you, have you?". PP4 had offered to speak it, and with encouragement went on to do so.

"So, the beginning bit is…I am blind but I am breathing, I'm blind but I am breathing, I can't see, but most importantly, my heart's still beating. No sight, but I still have a vision. Inspiring many, that's part of my mission. Changing lives, that is my huge passion. So, it's time to put my plan into action. I may have c a n c e r but take away the c e r, I believe I c a n, can win the battle and win the war. And then there's other parts…but…." "It sounds good!" remarks PP2, with me adding, "thanks for doing that. I did not want to put you on the spot.” Then, turning back to PP2, I’d acknowledged “it is going to be quite, quite a striking piece, isn’t it? Which is great. And it is similar to your work PP2, the imagery is quite strong if you know what I mean? What is the inspiration behind that piece of artwork that you are doing. Where did you get the image from?”

PP2 had responded, “Ideas will kind of pop into my head, but I wanted to do a piece that sort of like inspires people to just keep on moving forward. Like, you can overcome it. It does not have to, like, bring you down. There is always hope. And that. And then I just sort of like scan images online and see what I sort of like, what that photo is portraying to me. And see if that matches my idea and then I will draw it from there.”

I’d then gone on to ask about the artwork PP2 had completed in school, including a piece displayed beside a public motorway in Kent. PP2 had explained, “the whole idea of it was to shine light upon men’s mental health. Because, between the age of 16 to 24 in men is like the highest rate of suicide. So, I wanted to shine a light to like, make people think of a man wearing that mask. Like putting on a face on the outside, to make people think that they are ok when actually they are not. And that is the boy crying behind it. I do not know where it is gone, but hopefully I can get it back.” I’d then offered to try and put the work in the exhibition if it was possible. PP2 reiterated their intention to chase the school for this prior work.

At this point PP4’s father had made suggestions regarding bringing the large artwork up to the site, and I had agreed it might look striking, saying, “I think, making statements is not necessarily a terrible thing. I do not want you to feel you have to be too twee or kind of safe about what you are doing. You know what I mean? I think you are going to get a much better response from the audience if you do not play it safe. So, do not feel you have to water down what you are doing or, what you want to show, because of where it is. Use this opportunity to kind of show off the creative people you are. And if that means things are oversized, overloud, it does not matter at all. So just throw those ideas at me – yep – that is perfectly fine. In fact, it is good.”

With the group responding positively to this, I then had wrapped up the session. PP2 stated it was nice to meet PP4, who responded that “I really like what you are doing. Its putting across the same, or similar message I am trying to put across, I think.” I then explained; “I am nodding because up till this point, we were kind of talking about themes and, I think, I remember you saying PP2 at first it felt a bit vague because there wasn’t too much direction? But it seems to have developed one on its own, which is perfect really. So well done for putting your suggestions forward.”

5.4 Workshop four

(11/11/20 7-8pm – Online)

Designed around The Curator's Handbook (George, 2015), the purpose of the fourth "Planning and Evaluating" workshop had been to think about practicalities such as exhibition space planning, safety, and getting exhibition feedback. I'd welcomed everyone to the workshop, explaining that more people have joined the project, but may not have been able to join this session. It was checked that PP4 could hear the discussion, as would not have been able to follow it visually. Then, all three PPs had been invited to introduce themselves and "to just say a quick intro about, you know, what you are doing here on this call and what you have been up to, up to this point. Is that all right?"

To begin, PP1 had explained "we have been working on this exhibition, and I have been working on some music to put up in the exhibition, for people to listen to. I have been working with *VocalBeats* – I am not sure if you have spent any time with them, but they are really good. You know, helping out with creative sides and especially music. So, I have been doing sessions with *VocalBeats* every week to try and create something for the exhibition. And that is pretty much where I'm at."

Next PP3 had introduced themselves as "a self-taught graphic designer. I started this year. And I focus mostly on automotive parts, a bit like the ones behind me, and I have designed one for the exhibition. Some automotive art with a livery – which is the stickers and stuff that goes on them. And I have also illustrated a pair of Air Jordans, so just a bit of fun but they came out better than expected, so I thought why not put it into the exhibition. Yeah, and that is me in a nutshell – graphic designer." I had also clarified that PP3 had only briefly been in contact with the *VocalBeats* musicians, and asking what the experience had been like, PP3 replied "it was relaxing".

PP4 had begun speaking next, saying that they "have sessions with *VocalBeats* and I have been putting together a poem slash song and – yeah – I have been able to finish it now. I have not recorded it yet, but the lyrics have now been done and finished. Yeah, I have really enjoyed it. It is inspirational and motivational, that's the point. And, just making a point to many people going through a lot, and how they should view themselves, that they are strong and so on. And they should be proud of themselves."

At this point I'd joined the conversation in a celebratory tone, saying that a big part of the call had been, "just to congratulate you really because we have got to the stage now. We have done what we said we were going to do. We have an exhibition together. It has happened before the fourth workshop which is this one, so we are just in time. And, you know, all three of you have done some amazing work for that, individually. So, I just wanted to talk through each of your pieces and let you know what is happening with them, yeah?"

Going on to discuss PP1s contribution, I'd then reported "the way the exhibition is working is that there are two levels to it. One level is down in the radiotherapy part of the hospital. There is a big, massive wall space there. That is where I have put up the visual artwork that we have had so far. And then upstairs in the blood test waiting area, which is a busy waiting area on the ground floor kind of behind reception area, that's PP4 where I walked you through when you dropped in the other week? That is where we have the big digital screen."

"The exhibition's kind of split between the visual artwork and the digital. Although, what I want to do is kind of combine the two in ways I will explain. Because there isn't any audio-visual downstairs, apart from static artwork, what I wanted to do PP1 is use your track over the top of a movie about everyone's artwork? So, have it as like, the audio track behind the whole display on the screen? The audio display on the screen is going to be everyone's work visually and digitally, but also PP4 kindly said - because everyone has done a label - *you remember I asked you to put some wording together for labels* - PP4s given us a label vocally."

"That's why, PP1, we were going to find out whether or not you could merge your track with PP4s vocal label, at the end, which I know you have been working on. How is that going?" To this PP1 responded, "Yeah, I can do that. I can get it done by tonight definitely. What [*VocalBeats* musician] said was that I could have it at the end of the track, if PP4s cool with that. So as the track finishes you then hear PP4s vocal message".

All had responded positively, and I then continued on, "So if you finish it in the next couple of days that would be amazing. Because what I want to do is get the visual, the digital exhibition going by the end of the week. So, I've put all the movies, all the visuals together digitally. I just need the audio for that, and PP4s bit on the end there, so we can launch at the end of the week. That is brilliant." The PPs then discussed how best to share the digital sound file.

I then asked PP1, "on your track I noticed you called it, was it *reaching out to millions,* is that right? And you had put your name down as an alias, was it *Apollo* or is that just something that you thought of at the time? So, on the digital label, on the screen when it is going through everyone's labels, do you want me to put the track as Reaching Millions and yourself as an alias Apollo?" "No, you can put my real name for that" replied PP1.

I then checked how the new creative software was going to which PP1 had replied "Oh yeah, it is really fun. It's like, it is quite addicting once you get on it." Maintaining the session's focus on planning, I'd gone on to say to the group, "Brilliant. And the way the exhibition works, all of you, is that it is going to run until the middle – end of January. So, if you come up with some more material that you want to add in, or that you want to replace what you have, you just need to let me know and I will do that, yeah?" The group had responded with "Ok," "Cool" and "Yeah."

I had then pursued with a display installation update, saying that PP3s foam boards had been delivered and installed early that morning before the radiotherapy department had opened. Turning the conversation to exhibition evaluation, I'd said that a passing radiotherapy engineer had commented "*is that someone's whose being treated here? Oh my god!* The engineer thought you were a designer," I'd said, "and they had exited the installation saying, *they've obviously got loads of talent!* So, I think it is going to make a real impact."

I had then gone on to say that more prints of PP3s digital drawings had been available and could have been displayed in more than one area, if PP3 was happy with that plan. Responding that they were indeed, PP3 had said, "So, even come January, come February, you know, I can exhibit something else? Something else to keep it fresh? I am really glad. I have not actually seen it in person yet, and it is only a minor thing, but it looks like with the image of the car was actually mounted – not mounted - displayed - a little bit high on the canvas. I think this is a printing thing, but it looked like there was a lot of white space at the bottom. And then at the top, the car was, the car didn't look centred?" I'd offered to crop the image, to which PP3 had replied, "I think we will leave it as it is to be honest. I have not seen it in person. It is only a minor thing."

I then began discussing how the PPs might have evaluated the exhibition in person; "one of my questions tonight for you guys was going to be when and if you are going to be coming into the hospital – I know at the moment it is pretty tricky with the restrictions – but sometimes you have appointments and you are coming in. I do not know if or when you are next due in PP3 but, you know, whenever you want to come and see it, of course you can see it. I will get you in. But the two pieces they delivered in addition, they are still wrapped. If you wanted to collect them and have a look in person, so you would not have to come into the hospital, I can post them out to you. It is up to you – something like that."

PP3 had considered this and suggested that posting may be problematic at this time. In response, I then offered to take more photographs of that piece, so that PP4 could have evaluated the pieces. "Yeah sure, that would be great" PP4 had responded. I had continued on, "No problem, this is your exhibition so if you want to add stuff and take stuff out you can entirely do that. And, you know, if you wanted to send some digital images of designs you have done since, for me to add to the digital exhibition, you know on the screen, then we can do that too.” “So, do not think you have to have these printed off massive pieces all the time, you can do whatever you want. Have a think about that, yeah?”

“That I can definitely do” PP3 had replied, to which I’d then asked “see if you can get anything to me by Friday, then I can get it into that digital exhibition that PP1s going to add the soundtrack to? See how you get on?” to which PP3 had responded positively. The group then discussed the digital screen size and its resolution, during which I’d said “I will let you see the movie before it goes up, and if there is anything you want to change its fine. That is what I am here for, to make sure you are happy with what is going in. Do not feel as though you cannot ask for changes and adjustments to things, yeah?”

I had then turned the conversation to the other PPs artwork contribution plans, inviting and giving updates. PP4 listened and responded to an update about the progress of their raised letters printed piece. “Yeah, and it is something even for someone like me. Obviously at a time like this we cannot all be all touching it but, say for instance for me as I cannot see, I will be able to kind of feel the letters as well.” I had then said to PP4, “So we were going to finalise that PDF today PP4, but you might want to make a couple of changes to the lyrics. Is that right?” “Yes, um, sorry for being difficult” said PP4, to which I’d replied, “Not at all”. PP4 goes on; “Literally it’s just two lines added on to a certain part. Yeah so, it is just literally minor, a minor few changes and then, yeah, good to go.”

They had agreed to get that finalised with the *VocalBeats* musician PP4 was working with, before the end of that week. I then went on to ask PP4 if he had understood correctly that PP4 had also still wanted to do some recording in a studio. Hearing yes, the I went on to explain how he had tried to arrange some studio work with [the hospital radio studio] but that they were “actually closed for this month. Because of lockdown, but I will keep trying.”

I had finished PP4’s contribution plan update by asking, “So at the moment PP4, with your visual piece and your voiced label that’s going to be on the track, are you happy that that’s enough content for you for the exhibition now, or do you want to add more?” PP4 had responded, “Yeah, I’m happy. I am happy with that. I think with the label, and so on, I want it to be longer. I’m trying to remember properly what I want to say, but making mistakes can be an issue.” “It sounded quite well rehearsed. I thought it was great” I’d then responded, checking that PP4 had enough time with the *VocalBeats* musicians to complete what they had wanted to do, and reiterated that it would have been possible to change or update the display further into the show.

I'd then began a new discussion, saying, "the other thing I wanted to talk about tonight is how were going to promote this show. So, I have put on the label that the hashtag can be used on Twitter, on Facebook, and on Instagram." I mentioned that I'd hoped people that were looking at the exhibition were going to give feedback on it through those means. I then checked this expectation by asking the group, "do you feel that is a reasonable assumption to make? Or do you think there's other areas I should be looking at to get feedback?"

The group had replied that they agree it was reasonable, but PP2 offered, "maybe another note to say *feel free to take a photo and upload your thoughts using #visualbeats* or something, just to prompt them. But I think, you know, if one person does it then hopefully another person does it." I then encouraged the group to share the invitation to feed back through their own channels, before explaining, "the original plan was that we were going to have like a message board that people can just scribble on. But, because of covid, we are not allowed to leave pens, shareable pens, or surfaces. So, yeah, we have had to fall back on the old hashtag thing I am afraid."

I had then also explained that I would be checking social media for exhibition evaluation and feedback daily, as well as checking on the display itself. The hope was, I'd gone on to say, that I could then have brought the feedback to future workshops for discussing, "whether or not they've taken the right impression of what you wanted from your exhibition."

"We have been talking about loads of things, and I just want to make sure I have covered everything. Is there anything else you think we should be talking about at this stage?" I'd asked. PP3 responded by asking "is there any chance the marketing team could do a couple of teaser posts on Facebook or Twitter or something, or the Royal Marsden pages. I don't know…" to which I had responded, "That is a really good question, and you are exactly right. The comms team usually really love this kind of thing, so yeah definitely I will be promoting it to them."

I had continued on, positively, "what I wanted to do was get the digital content sorted this week. They are going to be extremely interested in that. I did not want them to promote it before the show's gone up, because I am trying to encourage public feedback, rather than people think that it is a *Royal Marsden show*. It is more of a show by you, than a show by the Royal Marsden. Do you see what I mean? So – yes, my vision is that it will be really picked up by the comms team at the Marsden. And also, by Youth Music, because do not forget they are partially funding the research as well."

I went on to talk about the workshop content, saying "the idea now is that we really get this out there. I mean, the end point of the research project is that we are going to publish a report, a research report, with your work in it, and with your words in it. Like the words that you are speaking now. You know, this a recorded bit of research, so your whole experience, my experience, and other people's experience, is all included in that. And the visual stuff. So that is going to be in a published journal for the world to see."

"So yeah, this is – I hope – just the beginning. We just needed to get the show up and, as I say, it went up this morning." I'd then gone on to inform the group that two further participants have been recruited and began to describe their ideas during the consent discussion, based on what had gone into the exhibition so far. I had ended this update by saying, "the show is going to be added to and added to, but you guys have started it off which is the best bit," and the group had spontaneously applauded.

"Any other comments or questions or concerns at this stage?" I'd then added to which PP4 asked if there will be a standalone Instagram page for the exhibition. I explained that the initial plan was to see if the public will respond to what the organisation promotes through their existing communication channels. The group discussed this, and PP1 offered, "Yeah, I think maybe first see like how the people respond to it and... because there is probably like a lot of people in that area anyway that can look at it and engage with it in person. And hopefully, by spreading the word, you know. Because sometimes you are waiting for bloods or whatever, you might just talk to the person next to you about the exhibition. And then, hopefully, by word of mouth it just gets around."

I had agreed with PP1 and responded that, "I have also left my work mobile number there because obviously some, maybe some of the older generation, might not want to do things on social media. They might just want to send me a text, or they might leave me a voicemail. I have tried to leave it as open as I can." I then went on to ask the group if they follow the organisation on social media, and finds that not only do they not, they also do not all have active social media accounts. "What about other ways of promoting it then, besides social media? What other media do you use apart from social? Is it printed? How you're interacting with media now, in terms of podcasts and things like that" I'd asked.

PP4 had confirmed, "I used to use social media but now I can't because of my visual problems. I listen to - I know it sounds weird but - to YouTube videos. Does the Marsden have their own YouTube channel?" "I think they do" I had replied, "and when you say listen to YouTube do you mean listening to people just blogging or vlogging or whatever they are doing? Talking through things?" PP4 had responded, "Yeah, I listen to people just talk. Like even just general videos, sometimes I listen to if there is talking involved. Sometimes there’s certain things, and I paint my own picture in my head as well, what is going on.”

I’d proceeded with exploring this idea of YouTube and finds that the PPs who have deleted their social media accounts still engage with YouTube. I had asked, “do you want me to look into whether the Marsden can kind of help us put together a YouTube video with a lot of narrative around the project and exhibition?” to which the group responded positively, and PP4 had said “Yeah that definitely sounds like a good idea.”

I’d then begun to wrap up the session, saying “I have asked a lot of you, and you have contributed a lot of time. But if any of you are interested in helping with the YouTube video, can you let me know? You do not have to tell me now, but just have a think about if you’ve got some time.” I’d reflected on the COVID-19 situation, and the difficulty getting feedback “because we cannot give out anything on paper. Before, in exhibitions, people have just gone up to the staff on reception in radiotherapy and told them what they think and then walked off. So maybe I have got to find a way of capturing that? Because people just want to say something and move on sometimes.”

After pondering this situation together, I wrapped up the session by saying, “I think that you have done an excellent job. It looks really good, and I think we are going to get some good responses.” I’d continued on by saying “I hope it has been a positive experience for you, not too onerous getting everything done” before mentioning the two next month’s workshops and a “bigger chat around all the feedback in Feb. Does that sound ok?” The PPs had responded to this and end the session with “Yeah,” “Sounds good” and “No problem.”

5.5 Workshop five

(8/12/20 7-8pm, On the ward/bedside and online)

Designed around The Curator's Handbook (George, 2015), the purpose of the fifth "Putting the Show Together" workshop had been to explore the practicalities of putting up, invigilating, and taking down the exhibition. I had welcomed everyone to the workshop after making sure participants were visible for those with sight, and that everyone could hear. "I am calling obviously from the ward today, because PP5 has joined the exhibition group. They are just finishing up some treatment, but I will let PP5 introduce themselves. Please introduce yourselves so PP5 knows who is on the call, is that all right?"

After some introductions, including another new online patient participant (PP6), I'd continued to say they wanted to share a couple of bits of news about what is planned for the New Year, in terms of putting the show together. First, I'd said, I would appreciate updates on people's progress with their own works for the exhibition, "PP6, you are top left do you want to say first what you have been up to?".

PP6 mentioned they have been working on, "a song about what it's like, what you feel like when you get diagnosed with cancer", with a *VocalBeats* musician. "So far, we've kind of nailed the chorus. So, I have written a couple of poems, one for my Mum and two others just about how you feel with cancer. (The author) kindly printed them off to put them somewhere in the exhibition." I responded, "and you've now sent me two more poems right PP6?", to which PP6 responded back, "Two more yeah, two different ones. They are about cancer." I'd then lets PP6 know that they will have had PDFs of the poems "by the end of tomorrow to send through to you ok, yeah?". "Amazing thank you" PP6 responded, and I went on, "I will get those printed off on A3, two each, and I will get them framed and glazed and put up. And then obviously you will have a set to keep at the end, yeah?" to which PP6 finished by saying "Yeah perfect".

Next PP1 was invited to provide an update, to which they had responded, "So yeah, for the exhibition me and (*VocalBeats* musician) were working on a beat, because I enjoy beat-making and producing. So, thanks to (the author and a *VocalBeats* musician) they managed to get me a copy of Ableton, which is a software for making beats. And, I have had sessions with (*VocalBeats* musician) once a week to make beats for the exhibition. One of them is being used now, and we have been working on other ones since" PP1 confirmed.

At this point PP4 had tried to call in and I'd approved their entry to the session before saying, "we are just giving a quick update on what people have been doing. So PP1, I am sorry I think you got cut off. What were you saying you are finishing?" PP1 had repeated that they had been working with the

VocalBeats musician, but I'd prompted this further by saying, "so the video on Vimeo that's actually playing in the Blood Test Waiting Area, that's your music over the top of that right?". PP1 had replied "Yeah, that's what we did" and PP6 added, "Oh that is mad! That is so cool."

I had then turned to PP4 and claimed, "I'm leaving you until last PP4 sorry about that!". PP4 declared that was fine and went on, "I have produced a poem, lyrics for a song which I have been putting together. I have not been able to record yet. But yeah, I've put together some lyrics for it and it is displayed on this board sort of thing. How is the best way to describe it (the author)?" to which I'd replied, "Yeah, so we had PP4's lyrics printed on like a big – it is a massive A0 plastic board, you are absolutely right."

"And, because PP4 is visually impaired, he requested the lettering be raised up so he can feel it" to which the others responded, "Oh really?" and "Ah cool. That is quite cool…." I'd continued on, "They had to come up with a new way of printing so that it could be tactile. You have not been with the board in person to have a touch of it yet PP4 have you?" I'd asked. "No, I have not unfortunately. I haven't been at the hospital many times lately, and I am not there again until February, so it is a bit annoying, I have not been able to see it" PP4 had responded.

"Ok well don't worry, hold that thought, hold that thought a bit" I'd remarked, before inviting PP5, who is sitting next to them on the hospital bed, to join in. "Tell us a bit about your interest, why you thought this might be interesting to join" I'd said, to which PP5 had replied, "Yeah, I like the idea. The whole kind of idea of what is going on. The exhibition, and what not. I think it is really cool what all you are doing. I would like to get involved. I have just been thinking about ideas for the ways I can get involved. I do like music, I do, I play guitar, and I have been playing for a year now. And I was looking at actually getting into using digital audio workshops and what not. And yeah, I have considered a few things, and I am just kind of skimming the surface at the moment. Kind of looking at ideas for what to maybe do, to maybe do one thing, or a few things, or whatever."

I had then enquired with PP5 how things were progressing with help from the *VocalBeats* musicians, to which they had responded, "Yeah, we introduced ourselves and I think we are going to have a session soon. I am just sorting out what software to use for my guitar and what not so I can get my guitar talking to my computer, and then start recording something. Then maybe come up with something, then we can start doing some sessions." "So, I've got an update on that, which I wanted to wait to tell you until now" I'd interjected, before going on, "the iRig that you wanted is paid for and it's going to be sent next week."

“Ok brilliant” PP5 had replied. I’d also invited PP5 to tell the others a bit about the software that has been purchased. “Yeah, so basically for the year that I have been playing guitar, I haven’t actually dived into the recording side of things. I’ve just kind of done things by ear, and the interface is just something that will let my guitar talk to my computer. And it basically just means that I can record things, take a small snippet, and then reproduce it. And play around with the sound that the guitar has made, and then obviously put that into some sort of physical work that I can keep and show, and what not.”

After checking everyone else could hear and understand what PP5 had been saying, I’d asked if that is something PP5 is planning to exhibit or is there something visual also. PP5 had responded that, as part of their degree in aerospace design, “one hobby I do have is making drones and planes. So, I was thinking of kind of joining them together. I have never considered actually designing a drone on the computer first, but it is just something that I am going to kind of start merging together, and what not. And maybe try and make what I make better, by using the computer” to which the others in the group had responded “Yeah, that’s brilliant!” and “That’s cool, so cool.”

I then had tried to continue a conversation about putting together the show, “So I guess there is a few opportunities. There is, you could in terms of the exhibition do some kind of visual work. Maybe even collaborate with one of the guys?” to which PP5 had responded, “I would be so happy to if you can play guitar. I can’t play any instruments. I kind of do it all on the computer.” To which PP1 replied, “And we could think of a way. You could send me over chords and other stuff,” with PP5 also responding, “Yeah, I would like…I would really enjoy that...I am the opposite because I have no idea with all of the computer side. That is the bit I have no idea about, and that is why I’m quite excited to get into it yeah” “Yeah me as well” claimed another participant.

I had then encouraged PP5 to explore the new software over Christmas and checked that “you have got PP1’s connection. So, we can talk some more offline about that can’t we?” to which PP5 responded “Yeah”. “Good! Any other ideas around the exhibition, or anything else?” I’d asked, to which the participants responded that they had nothing further to discuss at that time.

I had then changed the subject by asking, “you might remember that last time we talked about creating maybe a YouTube video of the exhibition, so the people who cannot visit the hospital can see it, can interact with it, and see what is going on? The comms team here have agreed to do that. So, they are going to provide a videographer. But what they were asking for was whether any of you wanted to get involved in terms of being on camera. Or, you know, explaining your work or providing some music for it. Just some content, so it is not like a promotional video. We do not want it to be too promotional. It has to be more, like, your story really.”

As the PPs had responded positively to this idea, I ‘d then continued, “So, the only thing with that is obviously, with the current situation, is that it involves you being here. Or not necessarily, but it involves them somehow being in touch with you. It could be that is remotely, like this, or it could be that it is in Maggie’s which is the outpatient centre here. Or it could be that when you come in for an appointment, that they just catch up with you when you are here anyway. So, I just wanted to kind of open it up and say what are your thoughts about that? Does anyone actually want to get involved or people not want to get involved in that? It will be in the new year.”

Two PPs had responded further, “I would like to get involved” and “Yeah, I would like to get involved.” “What about the rest of you? Does that sound interesting, or do you need to give it a bit more thought?” I’d asked, to which two more PPs respond “Yeah I’ll give it a bit of thought,” “Yeah me too” and “If it was my work, I would be happy to talk.” “Good – that’s great – thank you” I’d said, before turning to PP4. “And PP4, you know in terms of your work with the musicians you are still trying to get a session where you can kind of perform and record your piece right?”. PP4 responded, “Yeah. I was told that next January sort of time maybe. In Maggie’s.” I then explained to the others that Maggie’s was a newly built support centre within the hospital grounds, run as a separate charity.

“So, I wonder” I had carried on, “whether or not we could do the recording of your performance at around the same time. We could use a videographer with skills - that are probably a lot better than me with a phone - to capture your performance. How would that feel?” PP4 responded, “Yeah, I don’t mind. That sounds like a promising idea.” I’d asked, “Are you sure? I’m don’t feel I’m getting kind of 100%” and PP4 responded, “I am not fully 100%. I will think about it, but yeah sounds like a good idea yeah.” I had then suggested they might have explored this further outside the workshop, and PP4 agreed.

I’d then looked around and indicated, “Good, all right then. I am trying to think what else we needed to cover today. Yeah, in terms of feedback from the show, The Marsden have put some content on social media. I don’t know whether or not you have had a chance to see that? I think it is on Twitter, Facebook.” The PPs said that they remembered receiving the link but had not seen the content.

I’d then continued, “What happens is, every time I speak to someone about the exhibition, they tell me all these wonderful things, and I think *can you just, either put this in an email or give us it in social so I can actually use it*. Like, I showed pictures of it to, to a research group today and some consultants, and they absolutely loved it. So, I just need to get that feedback. And someone sent a star emoji, and I thought *I can’t, I don’t know how I’m going to translate that into a research output.”*

The group find this amusing. “I don’t know, last time we talked, you didn’t seem like you were overly active on social media. So maybe that’s why we talked about YouTube as maybe a better way of getting some engagement?” I’d asked, and the PPs agreed.

At this point PP6 had also said “Can I ask you whereabouts are – you know – my poems. I was wondering where abouts they are going to be, be displayed?” to which I had responded, “So, what I was planning on doing was, was printing them separately and putting one in each of the areas. So one will be in radiotherapy, one will be in the blood test waiting area and one will be in the RDAC which is a rapid diagnostic unit.” “And like all places I can go, and see?” PP6 asks, to which the author responds “Yeah, I mean it is really tricky at the moment isn’t it, because the [young adult’s cancer treatment] unit is what is called a Blue Area, which means that it is considered a higher risk area than some of the green areas”.

“I am quite sure radiotherapy is a Blue, because it obviously has people coming from, you know, outside. But, yeah, I think that if you wanted to visit and see the areas, then do. I mean, one of my questions was going to be to you – as I said at the beginning – *who has got any appointments coming up*, so I can make sure that you see the spaces. Have any of you got anything coming up? I would not want you to come in just for that, you know what I mean?” PP6 had confirmed “I’m coming in tomorrow” to which I had offered, after ascertaining what time PP6 would have arrived, accompanying them to “the easiest one to see - radiotherapy”.

“Have you been down there before?” I’d asked. “Yeah, yeah. I have been there before” replied PP6. I had then continued, “Your poem is not up yet, so I don’t want you to go down there and think *where the hell is it* because I am getting the other two printed off. Have you got any more appointments after that?” I had discovered that PP4 may not be able to visit before the exhibition comes down and suggests this would be “a shame”, and that a solution will need to be found. I’d also learned that PP6 will be coming in most Tuesdays, the also agreed to arrange a visit with them, when their artworks are in the display.

I’d then discussed what may be possible in terms of the other PPs visiting, making sure there would have been something for the PPs to see (or hear) when they come into the hospital. I had commented to PP1, “sometimes I feel as though I am kind of short-changing you a bit because, although you have music in the videos, there is nothing kind of tangible to see. So, are you happy you know that you have got enough on display, or do you want to get some more material?” to which PP1 had responded “Yeah yeah…its good”.

PP1 had clarified by saying “it’s been like, it was so fun to make…” an automated beeping noise from a clinical machine at the bedside became audible, overwhelming the discussion. “Yeah, I love it. Like, even in my spare time I spend like hours just making stuff. Yeah, I really… *BEEP*" and I had interjected, "That is great. All right well listen, I do not want to keep you too long, and we have now got a beeping machine" to which PP5 had replied "Yeah, it is the story of my life. Beeping machines everywhere," and to which the others had responded sympathetically.

"Was there anything else you wanted to talk about this evening?" I had then asked, to which the PPs had said no, there was not. I went on "So, the next one of these I am going to do is on the 19th of January so, obviously, have a bit of a break over new year but I will keep talking to you about your individual projects. And, if there is anything just give me a shout. Otherwise, I hope you have a rest over Christmas and New Year. Try and relax and enjoy yourselves if you can." "Thank you" a PP had responded, and another said "Yeah you too" before the session had ended.

5.6 Workshop six

(19/1/21 7-8pm, Online)

Designed around The Curator's Handbook (George, 2015), the purpose of the sixth "Assessing Success" workshop had been to discuss feedback from the exhibition. After welcoming the PPs and wishing them a Happy New Year, I had noted "thanks for joining another one of these calls. This is the sixth one now, and there is supposed to be seven in all. So, this is, kind of, the last one around the exhibition which is up."

"You've probably all seen the photographs? I know a couple of you might even have been in and seen it in person. It is going to be up until the (date), then it comes down. Then there is another one of these, a wrap up call, on the (date)." I had enquired, "have any of you managed to see the exhibition, or have you been keeping away from the hospital at the moment?" PP3 had confirmed "I haven't been in the hospital for a while, so I haven't been able to see it yet" and PP1 had also added "No, not in person. Not yet." I'd then checked with PP4 who'd responded, "the first bit was with my parents. From what they were describing it sounds, it sounds really good."

I'd then followed on, "What we are going to talk about today is the conversations from the last session we had, check a couple of things with you about what people have said about *VocalBeats*. Then I am going to give you a bit if feedback from the exhibition itself, that we have had from the audience. And then I just want to briefly talk to you about the YouTube video, because those of you that have been in sessions before will remember we talked about the possibility of having a YouTube video done? That is actually happening, and they are going to be filming the exhibition this week. But first, to talk through some of the comments people have made previously about the *VocalBeats* programme, I just wanted to check with you a couple of bits from it. So, who amongst you is still seeing the musicians?"

The PPs had responded that they were still having sessions with *VocalBeats* musicians. PP6 carried on saying "it is going well; we have nearly finished our song. We have just got to record it basically, and then a bit at the ending we need to do. They told me basically that I think they have only got a few sessions with me left?" to which I had asked, "and is the song they are helping you with for anything in particular? Are you preparing it for something?" "I don't know. I think it was for this, to show it. VisualBeats and everything" PP6 had replied.

I'd then asked how far off the song is from completion, and hearing that it would have needed at least two more sessions, offered "so we can talk a bit more about the video and whether or not you want to provide it for that. But they are planning on starting filming for the video this week, so we need to try and get some material for that, music wise, soon really." Thinking more generally, I'd gone on to say “in terms of you carrying on with your workshops PP6, what I have said to *VocalBeats* is – if they need to continue a relationship with one of the artists to get something done, or because it has been really helpful, then they should do that. So do not feel as though it has to stop suddenly after a number of sessions.” PP6 had responded positively to this.

I had then asked the same question to PP1, who’d replied, “Still going on. We started making a track for the video. It is basically that I just have to make it three minutes, I think. Or a bit longer than three minutes. So, I just need to find a section that I can, like, repeat. Yeah, because they told me that a YouTube video is usually maximum three minutes. So, if it is a bit shorter it should not be too much of a problem. It is not…yeah – it is not perfect; it has been really hard to get all the volumes right and stuff.” I had responded with “I am sure you are being very modest PP1 because the last track you did was fine! I bet it sounds really good” and another PP added “Yeah it sounds really good.”

I’d checked the timeline for completing the track, then reiterated that *VocalBeats* sessions could have gone on beyond the exhibition project. I had continued assessing for artists successes by turning to PP4 for an update, who said, “The song is written. It is just the recording. I know it was this month we were going to record. Because all what happened with covid and so on, that has been put on hold. But yeah, we have just got to record that’s it. I have a session tomorrow.” Again, the I’d reiterated that sessions could have carried on beyond the exhibition project, if necessary.

Next, I had begun a new topic with “A couple of themes came up when I was looking at the transcripts from these previous meetings, I wanted to check with you that – you know – my thoughts on what you were saying were correct. So, a couple of key words kind of stood out. One was that *VocalBeats* seemed to be helping you improve a skill? A skill that you have got. And I am seeing you nodding, but would you all agree that is one of the features of the programme?”

The PPs had replied “Yeah” and “Yeah, definitely.” I’d gone on, “And then another comment was about how they kind of improve your writing, they make your writing deeper or different? I guess for you PP1 that would be around, you know, making it a bit more complicated or complex, the kind of music that you are making. Is that also a correct assumption to pull from the discussions?” “Definitely yeah” PP1 had replied.

Checking with PP5, I had then asked, “What do you think PP5? You do not seem convinced,” to which they had responded, “I don’t know if they help me with my writing. Usually, I write the song and then come to them, and they help me musically. Rather than with the actual words.” I summarised by offering “they can kind of push you a bit in new directions, and I suppose that could be writing or musically? Is that also something that you would say is true of the *VocalBeats* guys?” to which the PPs had responded with “Yeah” and “Yeah definitely” and I’d confirmed this with “Yep you’re nodding.”

“A couple more things” I’d then said, “people were talking more about when they are in the hospital. They were saying that just being involved helps people to relax a bit and takes their mind off things, and that that helped in some way. Is that something as well that you felt?” “Yeah, that’s probably for me the greatest benefit” proposed PP3, and I’d followed this with “and PP6, you’re nodding as well there?”. PP6 had responded with “Yeah 100% I feel like, when I was in hospital or going through treatment and everything, um, the only thing I really had to look forward to had been *VocalBeats* and [music therapist]. The musical side to what the hospital offers, basically, was the only thing really like keeping my mood up and, you know, making me feel – like there is something to look forward to in the week?”

I had taken this as an opportunity to ask, “it is interesting you mention [music therapist]. I do not know if PP1 and PP4 met [music therapist], he is the music therapist. Did you meet them?” “Yeah, we used to go to sessions.” I’d then carried on with this line of inquiry by asking, “what would you say is the difference between what [music therapist] offers and what the *VocalBeats* musicians offer?”, to which the PPs had replied “I don’t know. I think, I wouldn’t say such a difference, there is a difference because obviously they have different ways of looking at music – like anyone would individually?” and “what they’re offering I thought like it’s the same thing. It is just like, an escape from what you have to deal with on a daily basis. Do you know what I mean? And just bring positive vibes and you know and helping us learn something that we are all interested in.”

I’d then asked if the PPs mean that the positive effects are mostly felt in the session, or also beyond them. “Even now yeah. It is something I look forward to and you know, like, an hour or two passes by and music – I am into music anyway. And it is like, with [*VocalBeats* musician] it is almost like just having a chat with a friend. Cause he really likes music, I really like music, and we can just share things and, yeah, it is good. I did have one criticism; I did tell him today. Was that I think he is too nice.”

PP1 carried on responding, “He never tells me what is bad with my music, points it out. I would appreciate it, like, if he would point out that this bit kind of sucks and you need to change it out. I would not mind if he did that.” “That’s really interesting” I’d asserted, and continued on further, “did you have that feeling, did you experience that PP4 and PP6?” to which they had replied, “Yeah um I really get on with [*VocalBeats* musicians], like we usually, we have an hour together. Last time we did two hours, because they had some free time. We usually end up like chatting for half the session before we actually get any music done. So very much the same in the sense that of, like, building a friendship with them."

I went on again, "it is interesting your comment, PP1, you were saying you kind of hoped they might almost be a bit more critical of you? Do you think that reflects the fact that you are kind of growing as an artist, and you feel like you can take that criticism a bit more?" PP1 responded to this with "Yeah, I mean, generally I'm very what is the word, like, I am quite a hard critic about…to myself. And I really appreciate when others are too. Especially if I feel close to them. I don't mind them saying, you know, you should do this, or you should do that. Because I know, like, it would lead to progression. Sometimes when I hear some of the older stuff I have made and shown to [*VocalBeats* musician] I think *there is no way he actually thought this was good*. He just says like it is all good. But yeah, I think it would improve the process if they were a bit harsher."

I had pursued this topic of creative feedback with PP4, who offered, "I feel that [*VocalBeats* musicians] have actually pushed me. I have to come up with it in my head and tell them. They have to type it down cause unfortunately I can't write, because I can't look back at what I have written unfortunately, to tell them. So, I have to remember things in my head a lot. But they have improved how I think and write metaphors and all the technique which I forgot about since, I have to admit, since I left school. That was many years ago. But I have built like a friendship, and they have helped me with my confidence and helped with my mental health as well" PP4 concluded.

I had acknowledged PP4 and went on by saying, "the last comment I wanted to check with you was what people have said before about them being kind of inspirational, but also like motivational for you. And I guess motivational means, you know, all sorts of things to different people. Am I right that is your feeling? That it has been quite an inspirational, motivational kind of experience working with them?" The PPs had responded to this question with "Yeah 100%" and "Yes. Definitely, definitely. 100%."

I then had thanked everyone for their contributions to that discussion, and introduced a new topic by saying, "moving on then a bit. Talking about the exhibition now, I just wanted to give you a bit of feedback that we have had from that exhibition. I am going to read these out, so I hope you can hear all right [facilitator reads out comments]. So, someone said its inspirational, and another that it is moving. Have you got any comments on those two bits of feedback?"

The PPs had responded to this with “just nice to hear I guess” and “Yeah. It is nice to hear about feedback from something you have done.” I then went on, “what words, are there any particular words that I just said, that jump out at you and kind of resonated with you more than others, or?”

The PPs again responded with, “I feel like when you said like the emotional side of it” and “I was going to say the exact same – yeah – the exact same.” I had asked “What about that? Is it because there is an emotional connection between you and the audience, or do you feel, that you feel exposed by that, or is it a comfortable feeling?” PP4 reported, “it is something I wanted to portray, the emotion, and try and touch people’s emotions. In my song, that is what I wanted to put across in general so, yeah,” which the other PPs agreed to.

I’d then continued, “and then they were talking about the fact that the exhibition is varied, and that it reflects you differently. Do you think, I mean obviously it’s difficult for you PP4 to comment, because you’re only able to go by a description of it, but I guess just the look of the exhibition – from what you’ve seen perhaps – PP5 and PP6, and PP1, the photos, is it what you were expecting to see or is it different from what you were expecting?”.

PP5 responded first by saying “I don’t know if I had any expectations, I just thought it was something nice to do. And obviously, like, seeing the pictures of – I think is it PP7 – her dog and everything, and all that, I think it is really nice. Yeah, just nice for people in the hospital to see.” “Have you got any comments on that, or?” I’d then asked PP1, to which they had replied, “Sort of the same. I did not really know what to expect going into it, because I have never really seen an exhibition before. Especially one in, like, a public place. So it was, it is an experiment basically and yeah, it’s cool the way it turned out.”

I had then continued to PP4, “from the descriptions you had of people’s work, was it what you expected, or different, or?”, to which they’d replied, “I am just really impressed by how talented everyone is, in their own unique way. Either at art or writing or music or whatever it is. It is nice to see that despite what we have gone through and so on, we still have talents, and we are still able to show what we can do. Yeah, and express ourselves – it’s a form of expression. It is just, yeah. Sounds amazing, the fact that we are able to display that in this exhibition.”

I’d acknowledged this comment positively by saying “well its good you say that. The last comment I have got to read is actually about your work PP4. Someone said, *We Never Give Up… a very powerful piece of poetry*.” The PPs responded to this feedback with “Wow!”, “Wow, that is lovely” and PP4 with “Yeah that’s cool”. I then pressed for further responses on the feedback. “It’s…I didn’t expect it.” claimed PP4.

PP6 added, “I think that’s amazing feedback. I think that it’s lovely to know that – you know – what PP4s written has touched somebody else and, like, made them understand what – I mean – all of us have gone through, our own different things. We can all kind of relate in the sense that, you know, how hard it has been. And the fact that someone else, like, can understand someone’s work and relate to it, and relate to any of our works is amazing.”

I had then turned to PP1 and PP4 again for any comment on what PP6 said. “I am just, I’m just speechless at that. When I first heard, I did not expect that. Really my purpose was to have that effect on others, and the fact that it has, that has really touched me. So, it proves what I was writing has actually worked, in a sense” suggested PP4, before continuing, “and, I even think it may have been [*VocalBeats* musician] that said that it ran, that it went on in their head as well, my beat. So, yeah! I am really happy; I am really happy it had that effect on someone.” When asked again PP1 added, “I mean if that was PP4’s goal then that is probably like the best outcome. Great.”

I then had gone on to read out feedback from a member of staff said *[It gave…beginning treatment]* and asked “I was interested in this comment about ownership of a space and wondered if you had any thoughts on that. About the exhibition as, kind of owning a space in a hospital?” The PPs hesitated, saying “I’m not too sure what they mean by that” and “No, neither do I.” PP4 said, “I guess it is a sense of – and maybe I am taking it in a different way what they mean – but I guess it is that art is representing a part of the hospital. The patients which are there, and so on. Just in a small way.” This explained things better for the other PPs who had responded with “Yep,” “That makes more sense” and “Yeah.”

Pursuing this further, I’d reminded the PPs that this was a member of hospital staff speaking, who “might have a different feel for a hospital space than a patient would? A different kind of power relationship with the spaces. If you work there its different than if you are being treated, I guess, isn’t it?” they asked the PPs. The PPs had been reluctant to agree with this.

I’d then gone on, “Alright, now this is the slightly challenging bit because we also had a piece of negative feedback. So - you know - we are all about the good and the bad, eh? A bit of criticism. This piece was in the upstairs area. You know, where the video screen was? And I put up multiple posters there of PP2s *I Beat It* picture? And it said underneath *I Beat It* and there was PP2’s drawing of this lady kind of like celebrating, it looked like a celebration face. Slightly – I do not know if its celebrating or slightly kind of angry. Do you know the one I am talking about?”

As the PPs had said yes and that they think so, I had also continued on, turning to PP4, "it is difficult to visualise that one PP4? But I put I put 6 or 7 of these pictures in one area, and someone said that a couple of patients who had a terminal prognosis for their treatment - so they'd been told obviously that the treatment wasn't going as well as it could have done - they thought that *I Beat It* as wording was a bit inappropriate."

I had continued further, "One lady was upset that she had been given the news she only had a few weeks left to live, and that the poster didn't really help her, mentally. So, when I got the feedback, I had said to the Matron *what do you want me to do about it? Do you want me to change the artwork around?* and she had said *yes*. I had said, *do you want me to do that immediately?* and she'd said *If you could*. So, I said *yes of course I can* and kind of did a swap around with some more pictures there, from you. I know PP6 one of yours was there too". "Two things there" I'd said, "what do you think about that bit of feedback, and also do you think about my reaction to it?"

PP6 responded first with, "I completely understand the feedback 100%. Like, finding out your cancer's terminal and that you have only got a few weeks to live. And then, obviously on the other hand having someone celebrate their treatment working and stuff is a different pathway, and it is quite hard to cope with your own emotions I can imagine. So, and I think your reaction was perfect in the sense of just take it down, or just move it somewhere else. And, you know, not to – not to kind of – the artwork that the person (I think PP2) made that is to celebrate, you know, how he is getting along. But that might not resonate with somebody else? So, yeah, I completely get what you did."

I had then asked, "What about yourself PP4, did you have any thoughts on that?", to which PP4 responded, "I completely agree. I couldn't say anything different. I think someone could look and relate like *yeah I beat it* because it is a representation of me? And there is unfortunately going to be a lot of people who are the complete opposite. Where they are terminal or so on. So, its – yeah – it is very sensitive, it's very sensitive. And it can be, it can provoke two, provoke two different reactions. But I think you handled it perfectly."

"And what about yourself PP1, have you had any thoughts on that?" I'd asked to which PP1 replied, "it is like a grey area. When you could get good reactions or bad reactions and, I mean, as long as PP2 understands that the hospital – you know the Matron – is saying that it is better to change it up, I think, just follow that advice is good". I had then offered, "It was interesting for me because I think, I think the sentiment or the spirit behind the image by PP2 was more about its link with VisualBeats and, you know, that kind of play on wording a bit. And, it was more about a kind of positive mentality, than about cancer itself. Particularly because everyone's interpretation is going to be different. You get it all the time with humour. And things, um, an individual can see it in a totally separate way."

I'd then offered more to discuss, "Because the people there are not necessarily wanting to be there. It is not like they have bought a seat there, and they know what they are expecting to get. Like when you see a show, you know what you are getting into. Because it's more of a public place. Having more general artwork and general sayings is probably a safer option?" With the PPs nodding and making noises of agreement, rather than commenting, I had asked, "you're nodding as well aren't you PP4 and PP6" and added, "I guess that might show how hospital spaces are quite different from like an art gallery in that, people can't help being there, and some of them might not want to engage with…some people might, you know, actually take offence by it". "Yep" "Hmm" "Yeah" the PPs had responded.

Acknowledging that the *I Beat It* artist was not present in the workshop, I had then also added, "Unfortunately PP2 only got out of hospital at 6 o'clock so he is on the road at the moment. He could not join us. So, I just wanted to give you a bit of positive feedback from his work. Just to kind of balance it out a bit, and I will obviously give this all to them too. Someone wrote [*the unfinished pencil portrait…the strength of the piece*]. So, what do you think about that? Any comments on that? You do not have to but…it would be nice to know if you have." The PPs seemed to respond easier to this, offering "Oh, that's amazing feedback. Yeah, especially on art that's amazing feedback." "Yeah, yeah."

I had then moved the workshop conversation on by saying "Good – thanks. Ok that is enough of the feedback. So, in terms of the way forward then. The last step in all of this is the YouTube video that we discussed. PP4 was saying that – PP4 correct me if I'm wrong – but you were saying that, you know, these days you sometimes listen to YouTube videos and kind of paint a picture in your mind of what they're talking about? So, a YouTube video or a podcast might be a good addition to the show. Is that right?" "Yeah" PP4 had responded.

I went on to let the PPs know that the hospital communications team had arranged a videographer to make a three-minute piece for YouTube. That video would involve shots of the show with some music or audio over the top. "They also wanted to know if one or two, or even three people would be willing to do a short video of themselves answering one question, that they could use in the video. And they will obviously edit it and that kind of thing. It does not have to be you three, just because you are on the call obviously. I do not want to feel like I am pressuring you into doing anything you do not want to do" I'd said.

I'd continued to explain the proposal was that each willing participant might provide a short video containing a brief introduction, the title of their artwork, and to answer one of three questions. The first question is *what has it been like taking part?* the second question *what difference did taking part make?* and the third question *why did you think it was important to share your experience in the show?* So, what do you think about that as a proposition for a YouTube video?" I'd asked. "Yeah, really good" replied one PP, but another had said, "Personally I wouldn't participate in that bit, being on camera, but I understand why they would want to have a section of that." I had then confirmed if the PP would be interested in providing music.

"And then, also in terms of the audio, has PP5 been able to get you any samples over yet?" I had asked PP1. "No, I have not spoken to him yet. I know [*VocalBeats* musician} mentioned that, because of treatment, PP5s hands are a bit shaky. So yeah, he hasn't really been playing guitar. So, we are just waiting until he feels well enough to do something." PP1 had responded. I had then explained that time was tight but reassured that PP5 "did contribute – I don't know if you saw that he put his drone in the exhibition?" to which PP1 had responded "Yeah I saw that that's really cool".

I'd then asked PP4 about the YouTube video proposition, who responded, "I am in two minds. I don't really like being videoed but if I could do audio to answer the questions. I do not know if they would be all right with that." "I think if that is what you want to do, we should propose that to them. Absolutely" I'd responded to which PP4 had replied, "Yeah, I would rather do it that way. I can't look back at the video myself because I cannot see. I do not like something being put in the video which I don't know what it looks like if that makes sense?" "Absolutely" I had replied, "I think that's really reasonable."

I had then checked with PP1 and PP6 about their contributions, to which PP1 had said, "Um no I'd rather just stick to the music", and PP6 had replied "yeah I don't really feel comfortable being filmed but I don't mind answering the questions, same as PP4".

I'd confirmed, "So, if it were just audio questions only you might be interested in taking part?" to which the PPs responded "Yeah, Ok." I went on to say, "Yeah ok, that makes sense to me. I was not, you know, I had no idea what your answer was going to be for this. I will get back to them, Ok? Because the filming is on Thursday, I will speak to them about the video side of things. And I will give the other four people a chance to see if they want to be in the video as well, because they could not join this call."

I had then asked if there is anything else anybody wished to discuss this evening. PP6 had responded, "I just wanted to ask about the YouTube. You said something about spoken word. I don't know if, but yeah, I was just wondering obviously if my song… I do not know if my song is going to be ready for the YouTube video or anything like that. But I have a lot of recordings of me speaking my poetry and spoken word. So, I don't know if I can maybe put some, maybe one of those forward?"

I'd then responded, "would you prefer that? Would you prefer to have a piece in there of you, kind of, doing some spoken word rather than talking about yourself? Or about your experience?" "Yeah, maybe something like that" said PP6, to which I'd replied "that makes total sense. What about you PP4? Would that be more interesting for you than answering questions?" PP4 came back to my question with "I would like to incorporate both if that makes sense? Like, answer the question and then, and then mention a snippet of my work."

"Ok that's good" I'd confirmed, "I think what you are suggesting would make a much more interesting, a more creative video. What we want to try and avoid probably is a video that just promotes the hospital. Really, I want it to be about you and your creative practice. Does that make sense?" "Yeah" "Yep" said the PPs, and I responded with, "You are nodding, good. Ok good. Well, I am going to have to work fairly fast on it, so forgive me if you get messages in the next few days about this, ok? My plan is to try and get his video produced and out there so that I can give you the feedback from it on the 19th of February, in our very last kind of get together".

I'd then invited any more questions before the session ended. "I just wanted to clarify when you would like me to have the track, like, fully finished" asked PP1. I had then talked through the remaining *VocalBeats* sessions that PP1 had left to complete the track, offering "So shall I say that we should try and wrap things up in your Friday session?". "Ok that's cool" PP1 responds. I'd continued, "and just bear in mind, as I said, don't worry too much about the length. Because if there are these pieces of spoken word in it, then they might obviously reduce the audio track here and there. But, you know, don't overwork it if you do not want to."

PP6 then asked about how to send the spoken word to me for inclusion. I had answered, "if you could that would be perfect. And same with you PP4, I think you were saying that you preferred to do something in the moment? So, answer a question then perhaps do a snippet of work. Is that right?" "Yeah so, I will, I guess I'll send you an audio file. I just need to know the questions" PP4 responded. "So, what I will do for you PP4 is I will send you through an audio file with your feedback, and then also the three questions. And don't feel like you have to answer all three, you can just choose one or choose two or whatever" I'd said, to which PP4 had responded "Oh ok, ok that's good".

I then thanked everyone for their time and ended the session.

5.7 Workshop seven

(19/2/21 7-8pm, Online)

Designed around The Curator's Handbook (George, 2015), the purpose of the seventh workshop had been to close the VisualBeats co-curating project and to celebrate its successes. I'd opened the final workshop by saying "thank you for tuning in on a Friday evening. This was a bit of an experiment. At the end of the last call, I said to everyone "is Friday evening alright?" It has been quite a good turnout, so thanks very much. How are you all doing?" Introductions had followed, and I'd acknowledged "you might have seen each other's artwork but not actually each other's faces" due to the COVID-19 restrictions.

I then went on to explain that this was the last workshop that closed, and celebrated, their year of participating in VisualBeats. "So yeah, I really appreciate you guys hanging around for the project, and the whole exhibition!" I'd continued, "the exhibition has come down now. I took most of it down last weekend and most of you have your artwork back now. Just got a couple left to give back which is great."

I'd continued, "The purpose of this last workshop is just to kind of look back a bit at how that has gone, talk to you a bit about the next steps I am going to be doing because, obviously, your kind of work is finished! And give you some feedback from that video that the Trust created. But, as you know, the project is about the music programme as well, *VocalBeats*, so it would be good first to just hear if any of you are still involved in the music making programme. Is anybody still having sessions with them?" The PPs explain that whilst a couple continue their sessions with *VocalBeats*, that programme has begun to focus on the paediatric wards, as scheduled for the New Year. I had reassured that "the programme is going to continue in the Spring. So, the option is still there if you wanted it."

"What I wanted to just ask you today, is there any way that you think we could have improved the *VocalBeats* end of things? What could have made it better or easier for you to access it? Have you got any suggestions for that?" I'd asked, to which the PPs responded with "I was completely happy," "No covid being around I guess," "Yeah" and "true, true." I'd then asked whether the availability of face-to-face activity would have made much difference to whichPP5 had replied, "Ah I don't know I mean I guess anything is easier without this whole thing. The rules changing every week, so. I mean if you had both options at least, anyway, but obviously that is not something that like you can control, is it? Obviously." I went on to ask about the format and frequency of the sessions, but the PPs seemed to respond that these were satisfactory. "The only frustrating thing was that I wasn't able to record, because of covid" said PP4, and added "again, that's not, that's nothing you can control", which the others had agreed with.

I'd then asked if there was anything else, besides recording, that the group might have liked as an activity. PP1 had responded, "Not really. Because, even on the software side of it, you was able to help out. I think overall the project was really fun. Did everyone have enough time? I had enough time." PP6 then said, "I guess with me, I mean, the reason I did not really get involved too much is because I didn't have the time to do it. But I am a bit of an exception because I joined quite late on the whole programme anyway."

I had then told the group about the plans for music writing activities that were to be available in the Spring. Ensuring the request for *VocalBeats* feedback was not confused with the exhibition project, I'd said, "So thinking back now, again to our exhibition that has come down. Did you all manage to see the video that they finally created, yeah? Or PP4 were you able to listen to the video? Please tell me individually what you thought of it. Whether you thought it was a good representation of what you had done, or, or something else?"

PP4 had responded first, "I think it was really good. Obviously, I cannot see the visual aspect of it so I can only judge it from a certain perspective, but yeah, I liked it, and the music went well. I am in the background, and what you were saying, everything was clear. So yeah, I liked it." "Thank you. What about yourself PP5?" I'd then asked. "I was really impressed actually when I saw it. It all went together really nicely. I thought it gave a really good kind of overall idea of what was going on. And I thought the transitioning and everything in the video, the simple stuff, was actually really cool. So yeah, I really liked the video" PP5 had said.

"And we got some of your footage in there, your drone footage" I'd then said to which PP5 had responded, "Yeah it made me laugh when I saw it, I was like Oh!". I'd next asked PP3, who had replied that he agreed with the others, but also added, "I think, in person, the canvases and stuff, they looked really good in person as well. And you said you got a few comments from people who saw it in person. I would say the video was incredibly good and I would say it looked good in person. I would say that that the artwork on the televisions did not look great. They looked OK, but they didn't look as good as the printouts. That is one thing I would say" PP3 offered.

I had responded to this statement by asking, "because you have got quite a bit of technical knowledge around that PP3, why would that have been the case? Is it a screen thing? Is it a resolution thing - or what is it? Is it compression of video or?" and PP3 had said "I think it could be a compression thing. I reckon, yeah. Depending on the file format of the images and how the video was compiled as well. I am not sure what resolution the television was as well. It was more of a technical issue more than anything else.” I’d clarified, “you’re talking about the video that we did early on, right? For the waiting area” “Yeah.”

I had then responded by saying “I know, some of the other arts managers in hospitals were saying *it is very brave of you to try that*, because no one has sussed out exactly how to do this in a hospital. It is much easier in like a gallery where you can control, you know, the loop and the screen size and everything. Working off a TV in a waiting area was a bit of a tall order. But yeah, I agree with you I mean, a couple of times I went in there and there would be John Wayne playing on the screen, they switched over. So, I suppose if you are sitting there all-day checking people in for blood tests it is probably quite repetitive and, you know, they would turn it off. But yeah, that’s valuable feedback.”

PP2 was asked the same question by me and agreed there may have been compression issues with the first video, whereas the second YouTube video “was very well put together. You can tell it is done by someone who knows what they are doing,” referring to the organisation’s videographer. I’d used this mentioning of the videographer to give some additional celebratory feedback. “When he was filming the exhibition, I said to them *what do you think?* and he was like *yeah it is really interesting*. But some of you said its almost good to be there in person. I think PP3 when you came in you actually ended up chatting to one two people that were sitting there. Did you? When you came in if I remember rightly?”

With PP3 saying that was the case, I’d continued on, “What sort of things were you talking about? What was it like having those conversations in the kind of real world when the exhibition is up?” PP3 had responded, “I mean…because I have only been doing art for a short time, this is actually the first time I have ever had any of my artwork printed. So, I would say when I saw it in person and when I spoke to someone for the first time about one of my pieces, it is the first time I have felt like a proper artist rather than a hobbyist. So, that was probably the biggest takeaway, that was the very first time that I felt like an artist, and that was really special.”

I had then responded “that is good to know. And PP2 was smiling there, at the top. PP2 what were you thinking about when PP3 was saying that?” to which PP2 had replied, “Yeah, like I have had my work displayed in a few places. But it is very nice hearing other people’s views, and people that know nothing about the exhibition, know nothing about artwork at all, and just speaking to them and getting their opinion on your work is – yeah – it’s really nice to hear.”

“We’ll come back to that because I’ve got some more feedback for you” I’d continued, “But I just want to go down this route a little bit more, about how you felt having your artwork on display. PP4 and PP5, when you came in you were kind of saying that it felt a bit weird having some of your stuff on display. What can you say about that?" PP5 responded first, "what of mine was on there it was a little bit, well it was different wasn't it, to everything else. Cause everyone's was like a picture, or like lyrics, whereas mine was a full-on object."

PP5 had continued, "It was just, I never thought that I would have one of them displayed in like any exhibition sort of thing. And I am very, it was quite cool to be honest. I mean, especially when I like saw it on the video as well. It was kind of cool in the video when they showed it, and then showed the footage of what it can do, and the visuals from that, and what not. But you know it was just quite cool because it was something I created. And the fact that it was quite - it looked like it was kind of half destroyed - was a cool part as well because it shows that it is just not bought off the shelf. That sort of thing."

I went on to ask PP5, "Yeah, we had an interesting conversation didn't we around your drone. When you were putting it up, I was really interested in the side that had the stickers on and you wanted to display the side that had the machinery part and the, like the working part right?" "Yeah, the cats that are all on the other side" said PP5 in response to this, laughing.

Next, I had asked PP4 the same question about how displaying artwork had felt. PP4 responded with, "It was good knowing that, like a work, a piece of work of mine is being exhibited and people can read it. And I know it had that time you said it had received feedback, and then it, I guess it served its purpose. I wanted to inspire someone – at least one person – and have an effect on someone. And the fact that it did is what made me most happy" they said.

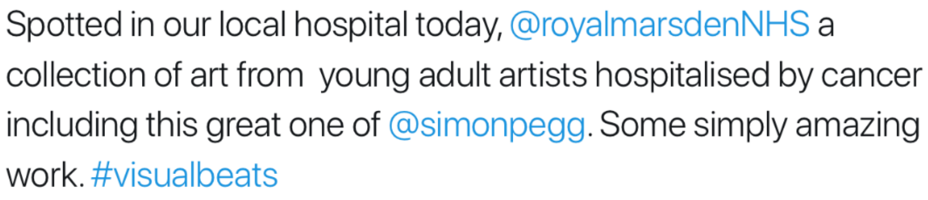
I'd pursued this further by asking, "I know that PP7 who hasn't made it tonight, shared some of the photos on their own social media, and I just wondered if any of you – I mean obviously you don't have to tell me. But I wondered if any of you have shared any of it between people you know, your friends or colleagues or whatever, and had any feedback that you could share with us? That I would not necessarily know about?"

PP3 had responded that they had shared one of their art pieces on their own page, "The version with the Honda Civic with the paint splatters all over it. I did post that on mine, and it got – I think it was my second-best response in terms of likes, and stuff like that. I got loads of engagement from it. So, I got very good feedback so far, yeah." When I'd asked the rest of the group, PP5 had said, "I didn't post anywhere particularly but I did share it with like, I kind of showed it to my friends. I wrote *ok* *look at this, this is what I am doing*. Especially with other people that I fly with as well. They thought it was quite cool. And peculiar as well, like to see one of them in an art exhibition.”

PP4 had then said, “I didn’t really share it, but it was good my dad got to see it in person when he came last week” to which I’d asked, “And what did he say? Do you mind telling us what he thought about it?” “He thought it was really good and yeah, he was happy. Everything impressed him” PP4 answered.

I’d then reviewed how the organisation had shared content about the exhibition project on their social media channels, including with the first time comment *we like to support the arts programme,* “But” I went on, “what I found with social media is that you do not get a lot back in terms of comments.”

“So, I think the time when we had the first social media piece about the radiotherapy exhibition, way back, the only comment we got was a gold star which I guess is a comment, but it is hard to analyse that kind of thing. But this time round it was a post that someone had actually put up themselves from the prison in Sutton called Downview. I don’t know if you saw that post. Someone that had taken a picture of a couple of the pieces – they had tagged Simon Pegg, because they had taken a picture of your piece PP2. Your drawing of him. And they said it was *simply amazing work*, talking about you as young artists” (see Figure 8 below).



Spotted in our local hospital today, @royalmarsdenNHS a collection of art from young adult artists hospitalised by cancer including this great one of @simonpegg. Some simply amazing work. #visualbeats

Figure 8 Diary image of VisualBeats social media feedback

“So, that was only member of the public that is actually posted about it” I’d asked. “We have had lots of re-tweets, and a couple of quote tweets where people said *keep up the good work* but no major kind of statements about the exhibition. I have had a couple of emails from people. Someone said to me *the artwork looks so good, all the work looks really accomplished* And I thought accomplished was an interesting word for them to use. Someone else wrote *I was very impressed – I loved those trainers* so there are those trainers again! Another comment I got from someone was, *very talented, very brave* which again I thought was an interesting comment. Another said *simply amazing work*, and then someone posted something that said *my friend* with some hearts, I think it was around – I think it was PP7 again. What do you think about those two words really *accomplished* and *brave*? What do those comments mean to you? Does anyone want to say?”

PP3 had begun, “I am very flattered I guess, especially with the accomplished part cos I have only been doing it about a year. And in terms of brave – I don’t know what to say. I really appreciate it though” and I’d asked PP2, who was nodding, and responded “I guess like with my work I always try and be like *quote unquote* brave with what I sort of do. I quite like to make a statement with all my work. You can see it basically through every piece I do. So, it is quite nice to be acknowledged for that one.”

PP6 was then asked if they would like to comment, and had said, “Yeah, I will definitely agree with the accomplished one because I mean, I mean all of the pieces of work that are in that art exhibition are, you know, everyone else, I thought they are really cool as well. And it’s an accomplishment to get to that point. That you can do that, so yeah.” I’d also asked PP4 if they would like to add anything, to which they’d responded, “Yeah, I agree and it is just to get that acknowledgment of, like, just the talent that is being exhibited. And some of us that have not been doing this very long. I think they’re great comments.”

Thanking the PPs, I had contended “it seems, you know I get the feeling that, we are all agreeing things have gone quite well. Can you pick out anything that has not gone so well? That you think could go better next time if you did it again? Be honest with me about this. About your involvement in the project – what hasn’t gone so well, what could we improve on? About the exhibition project this time. I do not mind who goes first.”

“Yeah, I guess I can start” began PP6, “one thing I could say, I know it is quite like difficult with covid at the moment but maybe it is like quite individual, everything I have seen. With covid its quite difficult to bring the group together but say, for example, this is the last meeting, and these are two people that have been doing this for like a year and it is the first time I have met them. Do you know what I mean? So maybe just a bit more integration with everyone. Like, it can still be individual work but just more of a closer kind of, er more involvement with other people I guess.”

I had then thanked PP6 and proposed we discussed this point, asking for any further comments. PP3 had admitted, “to be honest I would agree that - you know with covid it’s not possible but in the future, if possible - maybe a couple of sessions face to face would be great. But again, that is purely down to covid really. I would say a few sessions in person would be cool. And yeah, I mentioned the video and TV screen. If you could achieve that, but other than that I really enjoyed it.”

I had then clarified that being face to face, COVID-19 allowing, would mean “you are just a bit more familiar with each other and it is not such a new experience every time we have one of these calls?

You actually know who-is-who a little bit better. Is that kind of the where you are coming from with that?" to which the PPs had responded "Yeah, I would say. It is just to meet up as a group" and "Yeah I agree with that."

I then had invited PP2 to speak as they had had tried to do so earlier. "Yeah, mine is more like, for my specific work, I have that negative comment on my work. Well, I would not call it a negative but constructive criticism, you know. I had that on my work with the *I Beat It* poster. Maybe it's to do with location, or maybe it was just I didn't take into consideration my target audience, you know what I mean? I don't know if you heard about it, but one lady found it quite upsetting because she had only been given like a few days to live or something. So, yeah maybe like know my target audience, and taking that into consideration more. For future projects."

I'd acknowledged, "it is good of you to bring that up again. And as I said last time PP2, you know, I need to take responsibility for that as well. Because these kinds of decisions are, we kind of made jointly, didn't we?" to which PP2 had responded with "Yeah".

I had then asked PP4 the same question about things that could have perhaps gone better, to which they'd responded "like what has really been mentioned. It is all down to covid. It is nothing which you could have done yourself. Yeah, just getting interactive and seeing each other and, like in my case I didn't get to record. Again, that was all down to covid."

I'd then thanked PP4 for their feedback, acknowledging the impact the COVID-19 restrictions had had, before saying "going back a bit to what PP2 was saying. In terms of the decisions that we were making about what you have in the show, where it goes, how it looks, how its hung – because obviously, you know, you weren't necessarily there when I had to put some of the stuff up. What were your thoughts – has anyone got any strong feelings about how that went? Did you disagree with anything I had done, or did you feel like you might have wanted to challenge it a bit more. I can of hope that you might have been able to, but it is difficult. It is difficult at a distance. But how did you feel about your sort of control over the whole project?"

The PPs had responded by saying "Didn't have any problems really" and "It was more about how much freedom we had really – we had a lot of freedom. Like, I remember when I first talked to you and, you know, I was a little…well my concern was I do not really know what I can actually contribute to this, and I just told you what I did. And the – and yeah, we got something together in the short time we had. But yeah, I mean I don't think there was any real restriction anywhere, shall I say."

I'd also acknowledged this and pursued the question further with PP2 and PP3 by saying "really early on you were kind of saying I was not giving a very direct brief about it, that it is a bit vague. You know, what exactly do you want us to do for it? So how do you think that turned out? Do you think that was a good move? Or do you think I could have still had a bit more direction?" PP2 had responded first that they "actually thought it had to be a piece of artwork related to the Marsden, rather than just whatever we wanted. That was a little bit unclear. Could have been a bit clearer, you know, just whatever our specialty was. But yeah, that is hardly a complaint really." PP3 has also agreed with this.

"So, the last thing I'm going to ask," I'd said, "is about the whole process of it. In terms of getting consent from you to put things on social media and that kind of thing, do you feel as though you were given an adequate opportunity to agree to everything that was happening? You did not feel like I was making any decisions without your consent? You are all kind of nodding, but I don't know how you feel about that" I went on. "Yeah – I am happy. I'm happy yeah" offered a PP.

Referring to PP4's sight loss, and sending voice message (rather than an email for example), the I'd then also asked, "leaving these voice messages so that we make sure that you get them – has that been helpful for you? Have we done enough?" to which PP4 had replied "Yeah, yeah, it has been really helpful. That is how I tend to communicate with others."

Thanking the group for this further feedback, I'd next introduced discussing returning artwork, confirming, "the project, the research project as far as you are concerned as kind of artists is finished. What happens next is that I take the transcripts of these calls – so not the video – just the words from it, and I look through them for themes, and just things that have come out of the conversation that I think are interesting. All those things that I pick out are anonymised so don't relate them to any of you individually, more as a group."

I'd continued "My plan is to use those to write a research paper that will talk about the exhibition. I am hoping to include some photographs in there. So, I will stay in touch with you individually just to make sure you are aware of what I am doing and give you an opportunity to comment on that, but it will not be in this kind of group set up. Is that – does that sound reasonable, are people happy for me to stay in touch about things like the publication?" I asked. The PPs had all responded with affirmatives such as "Yeah sure" and "Fine by me." I had then discussed what will happen with the videos, and if they had agreed that the YouTube video could have been placed on the *VocalBeats* channel as a PP supposed "it's a good idea just to reach even more of an audience."

"In terms of other projects" I had speculated, "if you wanted to continue with some creative projects, I would contact you individually about any opportunities that come up. If you need anything you just contact me or speak to [youth support coordinator]. "That is it! It would be nice if any of you have got anything you would like to say whilst we are all in a group please go ahead. This is your chance, I guess is what I am saying!" "Well done everyone for what you did, I think it was really cool" declared a PP. "Well done everyone!" remarked another.

I then wrapped up with, "it is me that should be saying well done, because you have been great to work with. I have been totally blown away by your talent and your commitment. On behalf of the hospital, we really appreciate it. We know you've got a lot on your plate. So, stay in touch and anything I can help you with you have got to just let me know yeah?" The session had then ended with affirmatives and goodbyes.

In this section, I created an autoethnographically-inspired account of how patients collaborated and created within the VisualBeats workshops from the recordings and transcriptions of the sessions. I reflected again on the potential value of co-curating for enabling patients to supportively experience new agency within an institutional setting, which I felt had been suggested in the studies I had reviewed. The collaborating and creating loosely and supportively followed my intended steps from starting off with co-curatorially inspired ideas, to succeeding with an exhibition installation, and celebrating the co-curators' successes. This was despite some challenges faced by the COVID-19 pandemic, including the necessity to use video calling software to facilitate the workshops.

The VisualBeats workshops began with a reiteration by me, introduced in the PIS, that all PPs would be considered creative individuals and who together can form a new hospital cultural community (MacNaughton, 2007). I had hoped that this community would come together physically, however the COVID-19 pandemic dictated how this coming together was achieved safely in other ways.

Reflecting on this, I recalled that the research had begun with an understanding that, the hospital setting, face-to-face group arts in health interventions encouraging creative expression and peer-to-peer social encounters could be considered an effective design for supporting well-being (All-Party Parliamentary Group on Arts, Health & Wellbeing, 2017, Chatterjee & Camic, 2015, Morgan, 2013, Staricoff & Clift, 2011, Staricoff et al, 2004). PPs taking part in the VisualBeats workshops did so mainly online and were often unable to visit the developing exhibition sites due to COVID-19 restrictions. The participants were unable to meet one another and collaborate in person unless during treatment episodes.

Because of this, collaboration had taken place almost entirely within a virtual space. Exhibition-related images shared by me during the workshops included installation of the VisualBeats exhibition, as it developed. S. Similarly, any feedback about the developing and final exhibitions had to be relayed by me virtually. In some ways, the reader may agree having explored the collaborative transcripts, that this may have provided an opportunity for applying curatorial *field thinking* in real time (Mannay, 2016).

It is not possible to know if the workshops held online would have had different successful outcomes, than if they had been face-to-face. Technically, video-calling produced the desired outcome, which was a VisualBeats exhibition. In discussing virtually how to put together and exhibition, I'd been able to encourage the PPs to consider characteristics of other exhibitions that used similar feedback mechanisms, sharing images of those other exhibitions. I'd been able to develop exhibition content through words, images and videos.

Looking back to earlier reviews and the potential value of co-curating for enabling patients to experience new agency, perhaps that in one workshop the word "cancer" was not mentioned at all, and that all PPs produced artworks for the exhibition, is indicative.

In terms of supporting the PPs ill-being, at the very least, I had intended that the VisualBeats workshops would be caring and creative group encounters (Cutler, 2021Arts Council England, 2011 & 2022, DOH, 2007, Francis & Glanville, 2001).

I had also begun the workshops in the knowledge that hospital arts interventions involving patients creating artworks together in a social or group format can have a positive impact on those that take part (Sonke et al, 2015, Staricoff, 2004). Also, that the positive impact could be on both psychological and physical health (Warran et al, 2019, Stephens, 2017, Lyubormirsky et al, 2011), particularly in cancer treatment settings (Warren, Fancourt & Wiseman, 2018, Stephens, 2017). I needed to look, in the diary, for examples where I had applied my real-time field thinking to collaborate towards a positive outcome for the PPs.

Examples were found. In workshop one when PP2 began to talk about how they could contribute creatively to the exhibition ("I've only just started, like two months ago. But yeah, especially on the computer I just literally pick instruments, punch them all in and make a beat.") I, feeling this may be an opportunity to provide encouragement, highlight theirs and another PPs talents and how it can contribute to the exhibition. I also linked this to what I'd called the *point* of the workshops, "which is was to put on a group exhibition together", and "you've already started saying to each other you know what we can actually do together?"

In Workshop two I took an opportunity early on to share a fun "geeky" fact about myself. I was hoping to put the group at ease, before focusing back on the PPs interests ("with this project what I am really interested in is this kind of crossover between all the different creative things that you are doing"). Then, after sensing a lack of creative confidence in the PPS, I'd also explicitly stated that I did not want the PPs to think that there is a certain standard required be in the exhibition.

There were other ways, the reader may recall, that I had encouraged collaboration from all after sensing tension between being too vague, or too directive, sensing that ideas were taking time and effort to form into something concrete and reassuring the group that there was time to develop ideas further for them to happen.

Once the exhibition had happened, in workshop seven, I'd continued to encourage collaborative thinking, but with the burden of responsibility on me as facilitator, such as around the feedback about the I Beat It image. When PP2 had said they may like to know their target audience in future, and to consideration that more for future projects, I had responded that, "it is good of you to bring that up again. And as I said last time PP2, you know, I need to take responsibility for that as well. Because these kinds of decisions are, we kind of made jointly, didn't we?" to which PP2 had responded with "Yeah".

In seeking explicit examples of any positive affect of exhibiting to reflect upon, again examples can be found. In the final workshop PPs stated how nice it was to see their creations on display, to hear other people's views, and to feel like an artist for the first time. These positive aspects will be explored further, below.

A second stage of transcription and reflection explored my research diary of self-observation and self-reflection whilst facilitating the VisualBeats project. This was to address overall research questioning and reflecting around my own diarised experiences of the co-curating, mainly by giving the reader insights into the thought processes involved.

I had concealed my diarising from the workshop group and completed field notes after and between the workshops to avoid the negative influence on behaviour that a researcher visibly taking notes may have provoked (Emerson et al, 1995). Drawing upon curatorial sociology, my diary was structured to capture "curatorial tensions, mistakes, revelations, decisions, and compromises" from my facilitation (Puwar & Sharma, 2012). By also adding in a "Further Reading" prompt to my diary, I hoped to encourage "scaffolding" of my day-to-day curatorial practice with reflection and new understanding (Engin, 2011).

This diary took the form of a word processing package, made up of my research project field notes and images, plus personal emails sent to my own secure institutional email address over the course of the project. A separate file of electronic images was also gathered by me in a safe storage place.

I initially diarised entries separately as “field notes” and a “research journal.” I had intended the field notes element to capture self-observations and self-reflections around the co-curating workshops. As entries increased over time, all digital files were merged by me as one complete diary. Observations and reflections about curatorial tensions, mistakes, revelations, decisions, and compromises were completed by me when time allowed, and contained my varying points of view as a HAPM, a trainee researcher, and a facilitator.

As the reader will hopefully see from this account, my diary entries have enabled consideration of my assumptions, values, and beliefs, and how these may have impacted upon the research at the time.

The section will conclude with a summary of reflection following the completion of my diary, drawing upon Schön’s framework to explore what may have been involved in the technique (or “art”) of facilitating the co-curating (Schön, 1983 p18).

5.8 Before workshop one

In July, just before Workshop 1, my diary opened with the comment “Having weekly COVID-19 tests” which located my practical priorities at that time. I then reflected on where they are in the process of accessing patient participants for the study *(“conversation earlier this week about risk assessing recruitment. New patients are being screened by ward staff for the study, however it seems each one brings a new conundrum!”*). I noted the difficulty (due to COVID-19) of getting musicians onsite, especially as there had been an incident at another Trust where they had allowed in-person arts activity, then seen a spike in infections. I doodled an increasingly familiar in the diary (Figure 9 below).

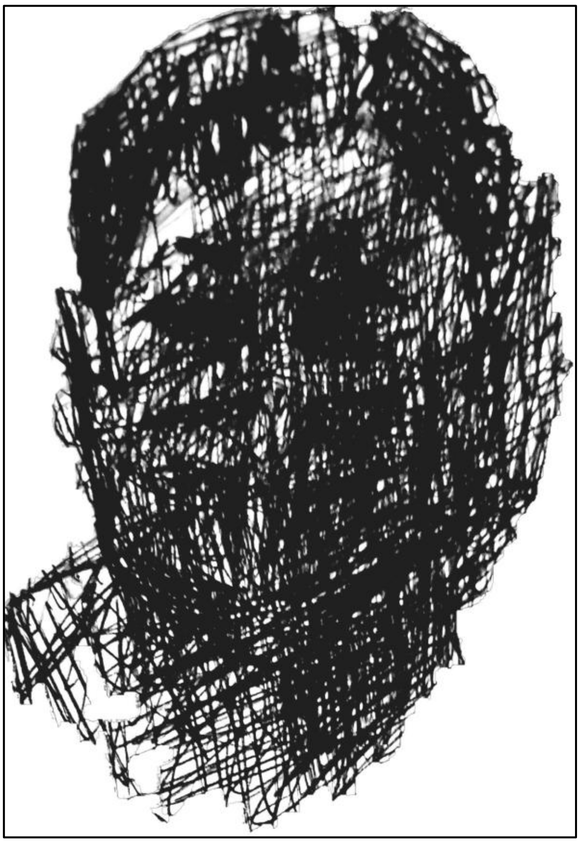


Figure 9 Image of diary drawing (July)

As the study was yet to get underway, I then reflected on the recruitment process (*“have a mixture of participants, some are inpatients in isolation (transplant) other outpatients receiving telephone consultations and living far away. I have been told that outpatients and inpatients are not allowed to mix on the ward, so cannot hold all workshops there. I have arranged for outpatient workshops to happen in the Maggie’s centre but cannot ask shielding outpatients to come in unless they are already on site for an appointment”*). I established that the amendments made to the study had been approved internally and externally but reflected on some recent precedents for experience-based co-design during COVID-19 from the Point of Care Foundation. I tried to re-interpret the protocol considering these new recommendations.

The following week I recorded emailing and screening potential participants for the study. I reflected on the difficulties I am experiencing with access, (*“Emailed participants, screened new participant. Was due to meet prior participant in clinic but DNA. YSC message to male prior participant ignored”*).

Over the following weeks I continued capturing the screening and recruitment process (*“Consented participant, arranged meet prior screen participant in clinic” “YSC met prior consented participant in clinic - seemed too keen to continue” “tried to meet and consent a prior screen participant in OPD but DNA” “Called prior consented F re evening workshop and she asked to withdraw from the study” “Called prior consented M re evening workshop and he said ok” “Spoke to prior consented M on ward and he also said ok*”).

5.9 Around workshop one

In the August diary I had recorded and reflected upon events surrounding, and during, the first workshop. The diary this month included self-observations, and interactions with others (*"catch up convo with YSC"*). I had structured my workshop notes to include a heading "tensions, mistakes, revelations, decisions, compromises," and this does provide guidance when thinking about the workshop (*"Surprised how quickly they agreed to work together" "Seemed to grasp the music/visual brief" "Tension between differences in creative ability*").

I had also structured in a "personal practice" heading to the diary, and for this period noted some positive and negative self-observations (*"Quickly put together a plan with touchpointing and a magic question" "Not great rapport building when panicking at start – disinterested but obviously what I say is important (talking about work) as brought up again by participant" "Lots of ums from me" "Didn't ask about artists that inspire. Didn't explore ideas/check understanding. Didn't make sure everyone on board. Didn't hear responses properly – emotional touch points missed?" "Responding badly, silences, not very encouraging" "Too business-like, rushed"*). Also included was self-encouragement about the success of the exhibition (*"Promise now worry about it later"*).

I had also included a "further reading" heading in the diary, identifying viable solutions to the issues raised (*"Looked at common mistakes in focus groups"*), and practical solutions for my methodological issues identified early on (*"Can I look back at the videos for reflective purposes?"*). After conducting reading, I record my reflections on my facilitating a group (*"realise I have only ever done 1-2-1 coaching previously. Also, the purpose was not clear (even to me). Can I change the purpose??"*).

Seeing that debriefing was recommended by the literature, I changed my approach (*"didn't have this – wait for supervision"*). Finding that those with less agency may participate less fully or openly, I think about the workshop participants (*"did I consider that some may feel more "talented" than others? Left one participant feeling disenfranchised, I was not aware of my focus on the other"*) and think about the impact of what was a small group size so far (*"if the group is too small each participant feels too much pressure to speak. Consider this? Or just desperate to have a group? I know instinctively the next needs to be bigger"*).

When I reviewed the literature, at this point, it was recommended that creating and maintaining a successful focus group environment requires more than one research team member (*"Oh, I'm on my own"*). I explored the moderator role (more below), before thinking about the workshop format ("*Was the scheduling ok? Evening? The only thing that went well"*). Then I returned to being more self-critical about how I managed the workshop group, and its individual participants (*"Should I have* *called PP1 afterwards?" "What role was I in, was it as a manager as that is my experience of facilitating groups?" "No ground rules, or ice breakers to make people feel at ease"*).

Reading common mistakes of novice (and/or nervous) moderators include failing to listen, to not tolerate silence, and talking too much, I questioned my facilitatory abilities. The emphasis of the diary entries had been negative, however, with little positive being reflected upon at that time (*"What went well – recording equipment!"*). I contemplated ways of running co-design groups within EBCD for inspiration, including the Point of Care Foundation Toolkit has a "Patient interview schedule" that covers Journey So Far, Issues, Best and Worst Bits (*"Am I getting patient focus groups and co-design mixed up?"*)

This month I also recorded thoughts about juggling the co-curating project with other (ongoing) areas of the arts programme, particularly with the added difficulties the pandemic brought (*"Thought a lot about difficulties I face – being part time worker, doing part time PhD. Music programme being hard to manage. But also need to be resilient")*.

My thoughts were recorded around how potential and actual participants were interacting with the arts programme at this time. I observed how much the difficulties were down to pandemic restrictions, or my research practice (*"Had a call with a potential participant who said he was "definitely visual art" rather than music. He also wanted to sign consent form digitally – a new one for me. Not signed it yet! But I did notice he had a clinic appointment he did not seem to be aware of. Tried to think if I should pursue that with him?"*).

Reflecting on my actions afterwards, perhaps I was balancing the overall potentially negative and disruptive challenges with the smaller positive advances (*"learned the VB team had been contacted by a participant to make some music which was reassuring. But another participant had gone home and not responded to my email. Tough"*). I had continued to look for solutions to these facilitation challenges, in wider practice ("*got Imperial's Zoom guidelines and made me rethink my approach."*).

The following week, my facilitation had gotten off on a positive note with regards recruitment to the research ("*Started week to find signed consent from last week's potential participant – great. Also identified he had an appointment morning of workshop – will try to see him then. Learning that important to arrange reminder on the day for focus groups"*). Elsewhere in the programme I had been arranging online activities.

At this time, I recorded my first discussion by email with a youth support coordinator (YSC), about the research (*"YSC said people backing off" "Interestingly when I mention music project and even though I explain it everyone is backing away. I am questioning whether it is musical fears and their interpretations or not having too good an experience. Any how I shall rephrase things and try again with others"*). I also reflected on the ongoing exchange in the diary (*"Re the project my only reservation would be that perhaps framing it as project that will mainly benefit nurses/paint them in a positive light (who they may not have had a totally positive experience of) rather than their own creative development, may put them off. It sounds a bit "institutional" to me and could be seen as slightly exploitative by the most cynical. I'd be inclined to just ask them to reflect on their experience of treatment creatively, and in any way they like. The VB guys should be tasked with pulling it all together." "Thanks Ben, OK I will do that"*). The YSC had then identified two more potential participants, one who has cerebral palsy (*"Will email intro the former and speak to parents of latter"*).

Although observing that recruitment is difficult, I reflected on this and reassured myself why this part was worth pursuing (*"Realised that although research is challenging it has to go on because cancer treatment continues, and inpatients are inpatients"*). I also reflected that that the recruitment process, complicated as it was, may need more fine tuning (*"YSC seems confused who is eligible for research and that they need to see VB first. Is setting up video calls prior to me contacting two males. Found out at end of day (in Chelsea) the one female screened is in Sutton today! Will try to pick up Friday"*).

In August, I reflected around observations from my supervision session that week, including a discussion about the characteristics of working creatively with young adults, and tips from one of my supervisors who does so (*"But does social feel like a void to them?" "Think of my role as a tutor/teacher"*). We had also discussed possible social mechanisms for co-curating as an activity (*"Show also gives them physical agency, control over how and where it is presented - it can lead to something"*).

I recorded actions that followed the supervision meeting, both for the benefit of the participants (*"Need to contact participants, give some encouragement"*) and for myself (*"Practice as research. Things happen through making. Keep it open ended like studio work"*). I had also reflected on feedback that I had sought about the site study protocol being restrictive (*"Protocol may be overcomplicated – told that's often the case"*).

I observed that I had gone on to arrange participant catch ups, by telephone and email. PP1 replied to say he was working on a musical piece and had a question about the length required for that piece, which I answered. PP2 was in the hospital when they called, therefore I had gone to meet with

PP2 and their father, where we discussed the workshop and their developing material. As the initial idea was that they collaborate, I fed back to each (*“Went back to PP1 (email) and said PP2 is working on ideas. Offered to link both up with musicians to edit material”*).

5.10 Around workshop two

In September's diary I had recorded and reflected on events around the second workshop. I had been thinking about the research and its relationship with the wider arts programme again (*"Thoughts over weekend - research has been a way to re-engage with the programme (catalyst)"*). I also observed challenges with working alongside the YSC to recruit patient participants (*"YSC had passed on wrong email address to participant for musicians. She's concentrating on other project with younger people. She's going away"*).

This month also saw an escalation in COVID-19 restrictions (*"UK Gov announced quarantine"*), which I contemplated (*"the whole thing has been a COVID-19 impact assessment log!"*). Much of the month had been taken up with navigating the restrictions to recruit participants, which was recorded perfunctorily (*"Emailed the PP with PIS and thought could set up pre-meet with musician?" "Tried calling a female PP."*

The following week I had observed reflections about the social function of the research during the pandemic (*"Had been thinking that isolation has been a recurring theme. Clinical and social" "interesting to think the p's did not catch up together in between "*) and its management in general (*"Paid for Zoom Pro. Things must carry on because of funding!"*). I continued to navigate COVID-19 restrictions to recruit study participants (*"PP has been in touch but hospitalised – sent consent but felt very strange. Sent reminder emails to 3 male p's, One replied. Tried calling other PP – phone number given by Lead Nurse was wrong?"*).

That month saw another steering meeting in the hospital, at which a moderator had been recommended by the Group (*"Had talked about moderators in both focus groups and EBCD"*). I had also then met with the *VocalBeats* musicians to discuss the research design (*"talked about linking up graphic PP with musician doing album covers but she seemed reluctant. Said didn't want to be too directive so ok. No further ideas – though mentioned animation"*). The musicians had mentioned other potential PPs, so I had taken steps to explore their inclusion in the study (*"Emailed YSC who is back Monday to discuss approaching these from next week"*).

I recorded and reflected on events surrounding the second workshop. In terms of tensions, mistakes, revelations, decisions, compromises, I began to form interpretations of the PP experience (*"Seemed keen to have a theme. Seemed to suggest artwork doesn't work well on social media"*). I had also recorded thoughts on the moderators notes from the workshop, which had been positive [See Appendix G)] (*"Didn't really need me (to keep time). Did not steer them. They need to talk to each other!"*).

I had recorded self-observations and reflections that were more frustrated about elements of my practice I felt should have been better executed (*“Still not really listening, distracted by Zoom? Hard to share artwork and idea. Still rather vague about timings”*). Again, I’d recorded looking for solutions to the issues identified, within the literature, including working with groups of artists (*“Group show initially – but no time?”*).

I had typed a passage from The Curator’s Handbook (George, 2017, p192) with words capitalised (*“The best curators are those who are used to working with and manging teams of people" “an INTERMEDIARY with focus on SHARED OBJECTIVE of arts and exhibition to be the best it can be”*). I recorded considering these in terms of my own prior practice (*“Thinking about the coaching or teaching aspect”*) and had taken concrete steps to develop my practice following this reflection (*“Enrolled on a lecturing and a seminar teaching course at Soton/UEA”*).

At this time, I had also discussed the moderation of workshops with my supervisors, and it was agreed with them that the groups were of small enough size not to require this. Other discussion topics observed from the supervision sessions included the difficulties with recruitment, and PPs trepidation around collaboration (*“Undergrads don’t collaborate either” “Creativity takes courage”*). We had also discussed university-specific doctoral administration topics.

The following week I had observed reflecting about how to manage the group between workshop sessions (*“Need to think about the gap between sessions. Suggested a FB group, or Messaging app? See that PPs from last week have not responded”*). This, I had noted, coincided with the UK Government announcing 6 months of further COVID-19 restrictions, including people working from home if they can.

I had also recorded and reflected that study recruitment continued, with challenges from both COVID-19 (*“Spoke to YSC about plans to remove unnecessary face to face contact”*) and general administration (*“Asked YSC about participants, confirmed I’d been given wrong number for one. Agreed can contact other pp family. Will do this when allowed in. Ok to underrecruit when discussing impact of pandemic”*). Solutions were explored (*“YSC agreed I need RM mobile phone and she will set up a message group - limited timescale, safeguarding”*) and found (*“Was given a phone!”*).

Finaly I also recorded and reflected that access to PPs required negotiated further (“*Spoke to YSC – said NK had advised to leave p for a few days so agreed I would contact participants new and old from the new mobile”*) and considered the new COVID-19 restrictions (*“Today has seen highest ever daily infection rate in UK, doubling from last week”*).

5.11 Around workshop three

In the October diary I had recorded and reflected on events around the third workshop. This month, I began with recorded observations and reflections on how having a mobile phone had made communicating with PPs between workshops easier, when working from home, and using messaging and calls (*"Really encouraged this morning to see messages from PP2 and from musicians. Started messaging PP1 then deleted – decided to call him instead"*). Frustrations continued, such as being usable to access all the required information to manage the study (*"Really annoying also not being able to see clinic details remotely as could check when they're next in!"*).

Within the diary I recorded reflection as consternation regarding the research, and exhibition, timeline (*"Had been thinking that if material is not ready it's not a big deal? However, PP that messaged said he will have some by next week, and the music PP is having a session this afternoon"*). In response to this reflection, creative solutions were explored with PPs in person and recorded as entries (*"Spoke to new PP for 45 mins. Did not want materials in voice or large text, didn't mention braille. Said can't touch things in hospital so relies on descriptions. Will come with dad to next workshop – and consent there. Verbal given"*).

The following week I had been able to access the hospital again, and this provided a better opportunity for recruitment to the research (*"Checked all screened and PPs for appointments in med records. Surprised to see a few opportunities!"*). Again, creative solutions were explored reflectively with a PP attending the hospital, which was recorded in the diary (*"Saw PP in OPD having bloods. He is coming every week (unless things change). Apologised for not attending workshop/contributing to chat. Seemed pleasantly surprised another PP had joined that he knew. I updated on what's happening – he still wants to do a new piece on A3 or A2 using graphite and iMovie. iPad pen is broken (had technical issues) – I offered to replace. Will poss meet up next week when he's an inpatient. Dad seemed happy"*).

I had also been reflecting around the time, place, and appropriateness of such exchanges for effective co-curating discussions (*"Reflections – felt a bit rushed too, sitting when clinical care happening. Ultimately felt like a good move"*). The location of the workshops was under threat at the time, for particularly good reason (*"Workshop next week – can't use ward as blue zone. Suggested Radiotherapy but that's too tricky, so have tried to book Gordini room. Has been deaths on ward (transplant) may explain reticence"*).

The earlier opportunities offered by the mobile phone, and messaging, also seemed to redefine the limit of my reach (*"YSC added me as admin, so I left a message. Welcomed new PP and reminded about next weeks' workshop"*) and to have been limited in terms of gathering research data (*"Been* *thinking how important the in between bits are. Can't transcribe my Messaging app messages so even more complicated to reflect on practice??"*).

Recruitment continued nonetheless ("*Went to adult ward to see first emergency admission with mum, gave talk and left PIH and Consent. Told they may get it back to YSC (or me) by 4pm or will take home. The other PP is not in great place but has now had a chat with YSC and has PIS"*). Also, I had recorded that the *VocalBeats* musicians were engaged with the research (*"They seem v positive about progress of research. Reassured no new material will be required – esp. for new PP who has already made some beats. Suggested p and new p collaborate musically? They had session with new PP straight after our Zoom"*).

The next week's diary began with a note on the deteriorating COVID-19 situation ("*Things hotting up nationally. 3 Tier system introduced yesterday"*), but my reflective actions led to relief that there was no impact on the forthcoming workshop (*"Wrote to infection control with plans to use Gordini Room. PC wrote back saying that's fine!"*).

Locally, I was considering the threat posed by juggling my research responsibilities whist working three days a week ("*Bit worried Tuesdays aren't working so well as not much time for me to catch up/too late to inform about the workshop? Let's see"*), but also that the PPs are also juggling busy lives alongside their illness and treatment (*"Have messaged YSC about the PP we met last week –she has relapsed and is in St Helier"*).

I then recorded the preparations that were being made for the forthcoming workshop. This included calling the PP with impaired vision to discuss the organisation of the session, but we had also discussed their creative ideas (*"Talked him through plans, seemed happy. Said will read out lyrics but I can ask musicians for some backup"*).

I had also endeavoured to make sure other PPs were prepared, but illness complications created obstacles to holding the planned workshop session ("*One messaged back to say has been in clinic and will join if can get home in time, and other said they are too sick to join. Last one did not answer. I came into the hospital anyway"*), and the COVID-19 restrictions, I reflected, added an additional complication for the exhibition itself (*"A bit worried as the Trust had sent an email around about re-purposing spaces and I'd seen desks creeping into the Blood Test Waiting area"*).

The October workshop session went ahead as planned, and both in-person and online. In terms of tensions, mistakes, revelations, decisions, compromises, I reflected that there were differences in levels of PP participation, and this concerned me ("Invisible tension – two participants not engaging. Needed to keep telling myself they do not have to"). I had also noted that the presence of a visually impaired PP, and his father by invitation, created a slight tension in terms of my facilitation (*"Anxious about giving enough consideration to new visually impaired participant, also father being there. Felt Dad was bored towards end as had been here a while after consent, also worked all day*").

I recorded myself reflecting on the workshop's creative discussion and content within the diary, including the potential for a shared "theme" within and around the artworks (*"Was surprised the two PPs had a similar theme of "Can," resilience, hope? Both seemed to interact well, empathise, very polite/respectful"*), and that creative ideas were developing ("*Happy that ideas are materialising - stop motion, written word"*).

In terms of my facilitation practice, I observed that I was more relaxed with the flow during this blended session, and able to respond better to cues within the workshop space (*"Discussion topics flowed and were added to pragmatically? Was comfortable with time"*). I remained somewhat frustrated, and related topics arose from this workshop, for reflection (*"Actually sounded a bit vague still. Was pleased when they spoke but on reflection I was biased towards the visual"*).

Again, I reflected around being conscious of poorly accommodating the visually impaired artist (*"Didn't really explore his other creative work beyond what he can no longer do - cor blimey - a low point of my response?"*). Also, I gave thought to the non-workshop interaction as a more effective creative space (*"Wonder if the Messaging app chats are more revealing practice-wise then the workshops!!"*). Further reading following the workshop, I had recorded, should be around artist statements, labelling, and QR codes.

The next day I recorded hearing from a PP that had not joined the session that had taken place the evening before ("Said he'd been incognito"). I reflected feeling reassured that the PP seemed eager to proceed and had been creating artworks for the exhibition, which they would then send (*"PP did this almost straight away, which I sent off to print team for quotes"*). I recorded also following up with another PP who had not taken part in the latest workshop but did not hear back. I noted having been also reassured to hear from a *VocalBeats* musician later that day that the PP had been creating music for the exhibition (*"Heard he is going strong, making a Soundcloud and messaging musician regularly"*).

At this time, I recorded that the COVID-19 restrictions had once again altered (*"London Tier 2 announced. Need to think of ways to protect the participants"*). I was also thinking about creative solutions for making the exhibition, many of which were in response to the difficulties of the COVID-19 restrictions ("*Realised timing of receiving work may be erratic – need a solution not half a show"*

"Use QR code –that is unfashionable" "TAKE PHOTOS OF BLOCKED/LOST SPACE and keep that email about spaces changing/take image of it for slides") with some opportunities identified, from the situation (*"Opportunity to have an audience during COVID-19 – people need to attend cancer hosps for tests"*).

Specific reflections were taking place around the material as a display, both (*"Surprised by responsivity of print room, cost of foam board" "Bit disappointed by ease of solution, bland? How to hang them?"*) and conceptually ("*Reclaim space/repurpose collection/decolonise? Also replacing means they are good enough?" "Thought about site specificity of PP's motorway work – reproduce that?"*).

At this time, I mentioned reflecting on a curatorial practice conference I had attended and written a blog about, in terms of creative ways to work with what would have been considered by museum and gallery curators as a conservative collection. I also made notes about a Frieze talk I had attended online (*"Enabling access as the curator, Relinquishing control as the editor, Having creative control, Making decisions for the artists – POWER"*). I recorded trying to put this non-directive, dispersed approach to co-curating into action when discussing a PPs creative plans (*"Spoke about the new invading space idea though not sure he liked it – said I need to see it"*).

Lastly, I attended an online seminar (UEA) and at the end messaged that it had helped me with the focus groups. However, this was at the same time I had completed transcriptions of the workshops (*"Finished transcribing and feeling a bit like I've left people hanging, PP4 particularly"* "*Bit agitated after transcribing on Friday. Am I doing enough to support them? Am I forcing collaboration?"*). I had also recorded a reflection around the impact the project, and wider challenges, were having on the YSC, and what I could to improve their experience (*"Met YSC today who seemed tired, stressed. Offered to help again with setting up a Zoom on Monday which isn't ideal but seemed to help her yesterday" "Helped YSC with her poster presentation which felt good"*).

I observed that the project took a more positive turn soon after (*"Turned out to be quite a productive day! I emailed PP the print quote and he came back with fully converted CMYK files, saying he'd learned a lot doing it. I wrote back with label template and said I'd photo new spaces tomorrow" "Discussed new PP who I was worried might not have liked workshop last week, with musicians. They said he had a plan. Left him a voice message and sure enough came back very positively"*). I reflected being conscious about the pace of progressing people's ideas, to not create any undue pressure (*"Heard out of blue from PP who was in clinic, to say will have piece next week. Said great and offered* *to repro other pieces if preferable. Also said would send sound files from other PP to select – waiting for that p to say I can call him to share these. He said can I call him tomorrow instead – PATIENCE!"*).

Reflective thoughts, captured in the diary at this time, had turned to the exhibition display and ranged from interpretation practices (*"Looked into QR codes and realised that they're big again because of covid tracing" "Realised how important the link is. Can use this show as a LOCAL artist showcase - will update labels to reflect that"*) to the audience themselves (*"Relief that the Rapid Diagnostic and Assessment Centre, Sutton is not just Breast but prostate too"*).

Within the diary I reflected on the pressure I was feeling myself, combining the VisualBeats exhibition with others taking place in the hospital (*"I'm juggling this with three other shows at the moment"*), and the importance of others such as the YSC in sharing some responsibility for recruitment, which created its own pressures too ("*This morning YSC said she can't as up against it - I asked how we will recruit new participants to programme if she doesn't attend these (second week). She called – said we can restart ward recruitment next week"*).

The recruitment process itself, even with YSC help, was also observed by me to have been pressured *("PP mum has wanted to email consent form! Received that form, added new PP on HIS, emailed her and mother. Voice message already. Other screened PP had not met VocalBeats yet!"*). Lastly, I had recorded including the clinical leads of the exhibition spaces in the plans (*"Agreed to a new display going up. Talked about patient throughput – breast, prostate, genetics. Said patients are anxious, no magazines allowed etc so would like something. Also talked about blood test waiting area – said could use that screen for MP4, that patients are coming from wards and MDU for phlebotomy. All about patients flows"*).

More discussion was recorded by me as taking place between myself and the patient participants. These discussions were focused on their developing ideas (*"Spoke to PP at 3pm on the phone about his tracks. Reassured him can keep working on stuff, add more later. Be experimental. He's happy to share "Bounce" with other PP" "Been back and forth with PP about experimental space. He offered some great ideas, keeping images together etc, just waiting for him to confirm what he wants. He also commented on/agreed label content"*). I had observed that this discussion created tension for me, between exhibition- and artwork-making (*"I thought my job would be to always just make SUGGESTIONS both aesthetic and technical? But I'm contributing to the video. And I have always liked QR codes aesthetically?!"*).

Within the diary I also observed and reflected that the demands of recruitment and facilitation were taking a toll towards the end of this week. One demanding aspect had been the volume of communication between the exhibition workshops (*"Looked at messages and decided – having been* *so busy and tired today – will launch into it next week, take shows down, measure up, order prints and label. Sent a message to new PP but left it at that"*). Time management had been difficult too, with interaction taking place after usual work hours (*"On way home from work Friday PP texted to say working on track and can add video to it. Asked him if should wait for new music or share [demo track], he said wait"*).

I had appreciated that PPs were facing pressures of their own at the time, which meant that recruitment was leaner than I might have expected (*"YSC emailed to say PP has been asked what he wants to do in relation the research. Says if he doesn't respond I think perhaps we just accept he is not ready at this time and wait for him to reach out to us again"*). I did also reflect on the importance of the YSC gatekeeping relationship (*"Have been thinking today – as had a message about a new PP from YSC – how important that relationship is"*).

The following week I recorded reflections around beginning to prepare the three hospital exhibition spaces (*"Went via Blood Test room and surprised to see very busy with TV on, hot too!"*). I had observed interesting responses form staff in the areas being prepared (*"First a? medic said Are you doing some painting? When I said No, putting up a new exhibition Oh really? Eyes roll walks off. Did not ask him to qualify that, worried will disturb his clinic as in clinic room?" "Second and third clinicians passing by - All those lovely artworks have come down Walls look bare"*).

I had then reflected around preparing labels and reflecting on the costs involved (*"decided to print as smaller corridor size so I can always exhibit PPs work with a label opposite if all else fails" "Bit nervous as already £500 spent if this goes through. Print Room guys is on leave today!"*). I also was thinking about the modes of display, and any associated costs, including video (*"Started researching looping media players for use on the screen as QR code idea was getting problematic/and as discovered players are c£40 would be more expensive? Asked Charity who owns the one in RDAC and the NPAG admin if they can ask colleagues about recommending one*").

My attention had then turned back to liaising with the PPs about their material being ready for display. I reflected on how difficult it is to know when patients might next be in a clinic appointment (*"How would I find these things out it they're not in the research??"*). Recorded catching up with the musicians working with the PPs instead and my being reassured (*"They said one PP's lyrics should be ready by tomorrow. Other PP track is finished"*).

Where I was not able to reach the PPs directly, and where they were involved, I had checked in with the *VocalBeats* musicians and YSC and was again reassured (*"Seem positive about 5 peoples'* *contributions"*). The musicians and YSC, I reflected, were also of help when discussing the planned display (*"Discussed media player over QR code. Also raised lettering for visually impaired PP. Also, projection! YSC has one...would need to be time specific not on loop??"*).

Within the diary I also reflected the instant messaging format set up by the YSC, to enable the visually impaired PP to receive voice messages, had also allowed for creative ideas to have been shared by PPs (*"In the group chat were many images of on p's pets. At first was a bit disappointed then realised it's an opportunity – can use them in the show?"*), although that not everyone had liked the continuous chat format (*"PP saying no one's listening to his messages and feels "left out." Looked at others and saw that in fact group had responded not long after he'd messaged me. Will call him this am. He prefers to leave relay messages to chat!"*). At this time, I recorded that the YSC agreed to try using the instant chat function to ask PPs for label content. I also recorded discussing this in a doctoral supervision session.

At the end of the month, I had asked other NHS HAPM colleagues if they could make any recommendations for USB-style looping media players for use on regular hospital waiting room TV screens? These would be to show audio-visual artworks continuously/on loop. I had been surprised that I was proposing a new curatorial practice (*"I'm afraid I don't have an answer but would be very interested to know too if you find something that works!" "I wish I knew the answer to this! Please can you keep me in the loop on any solutions?"*).

5.12 Around workshop four

In November's diary I had recorded and reflected on events around the fourth workshop. Entries this month began with a note referring to the implementation of national COVID-19 restrictions ("Second lockdown announced last Friday to start this Thursday"). Following (and despite) this the entries go on to reveal the process of pulling together an exhibition plan. I had been spending considerable time finalising the material and labelling with the PPs around my usual collection management responsibilities (*"Sent message to ask if anything being dropped off tomorrow so I can be available to pop in. Rearranged framing trip for next day" "Really happy to see label messages from two PPs"*).

Where artworks and labels were available, I described questions to myself around adjusting the display (*"Thought overnight about "creative contingencies": Can I try a USB of label text with PP1's music?" "What if the sound art gets turned off – can I print out sheet music as know you can do with* [music making software]*?"* "*Went and checked telly takes USB and it worked! Blood room was quiet, receptionist very helpful - liked watching John Wayne"*).

Questioning the artists' motivations was also included in the diary, as reflection *("My inkling is she just wants her art in but will let YSC query that first"*), where the lack of face-to-face contact imposed by the COVID-19 restrictions meant communication had to happen by message. When face to face contact did occur (see Figure 10 below), the results were more certain *("Got a surprise message from PP2 to say he is bringing work into hospital after all – amazing! Will ask him about stills when see him at 2pm. Met him after bloods – went to his car and discussed work (final piece and sketchbooks) lots of content military, children, some life sketches. Settled on faces and a poster – said a series of 3 seems to be working (with female p etc). Discussed still – said to email them through. Also talked about label. Said he is going to school, but I said we have enough – series of three. Sent him the photo, he confirmed wording for poster would be "I beat it"*).

Figure 10 Selecting artworks with a PP in the hospital car park (November) [Diary image]

At this time, I had used the diary as a practical reflective aid, with short To Do lists making up some day's entries *("Print out and frame the labels/identify" "Use PP4s verbal description in media" "Call p and re-consent re her 3 track EP")* and as a way to explore my own creative ideas for the displays, including when I decided it could be in multiple temporary exhibition spaces at once *("On way into work suddenly thought why not do three shows, sequential in the three spaces. Fill as we go – happy that I have three original artworks at least. Now thinking original, foam, poster, postcard (and digital). An RCT of exhibitions!"*). I had also captured thoughts on the formatting of the display itself (*"Re the hang – go for mixture between sheet music/notes and salon, interweave each participant's work? Also maybe use 3M for all, no poles"*).

The diary had also tracked how I was liaising with the artists to get their material and labels ready for display, including when cancer treatment created obstacles (*"PP messaged me to say she's relapsed. Offered support from YSC and said will check in on Friday. Sent off lyrics and dog photos as unlikely to get bigger files now." "PP who I made poster for liked it but seemed confused about printing portraits. Sent label wording – he asked for help with last line" "PP had sent three better images so that will work – also asked her about her track." "PP may do performance piece and vocal label"* "*Messaged graphic PP about using screenshot label – not keen"* "*PP said he tried* [movie making software] *but it was not basic and will email over images"*).

I had captured the re-joining of a PP to the research *("Reinstated PP left voice message reply – will catch her in clinic next week*" "*Met PP re-joining in clinic. Had seen she's unwell – looked visibly distressed but happy to re-sign consent. Said may skip tomorrow's session but will maybe join next one. I said she can think about content and discuss with* [VocalBeats musician]*")* and reflected on the tricky recruitment of a new PP during these restrictive times *("Messaged new PP about clinic tomorrow. Sent qualifying message about consent and exhibition as felt weird"*). Also, I had found that the research was not being introduced on the wards (*"Checked ward list and 7 pats in, 6 over 18. Emailed YSC and asked if could go and have a chat with them. She said fine but too busy to help and to avoid bed 9. Why are they not already engaged?"*).

The diary also continued to capture reflective moments of trepidation about my role as HAPM, but also as a creative individual, a curator *("Am I overly authoring the show?" "Overnight thoughts - I need to consider the overall aesthetic (like using series of 3's), avoid cringy/banal subject"*). I had questioned my own creative abilities when it came to realising the artworks (*"Have not done filmic before, except in art foundation and as a couple of promotional films at Chelsea!"*).

I reflected on enlisting others to find solutions for the artists within the diary (*"Decided to ask musicians to merge audio for film"*) including the print workshop *("Met Print chap Martin and discussed what's possible – talked about image quality, doesn't matter that much, PDFs, intaglio print"*). For the latter, I captured the detail of an email exchange that involved decisions around the formatting and printing off the images PP6 had chosen to display.

The print technician had cropped the photographs for printing in ways that I'd asked to be changed, to incorporate more of what I imagined PP6 intended to capture (*"Could you please try to include her bracelet/jewellery" "could you try to include the crutches at the bottom" "could we include more leopard skin sleeve"*). The artist responded positively to this ("*Shared dog pic with PP and she said perfect so sent to print"*).

It was clear from the entries that the project had taken up thinking time even outside of my three arts management days per week, with *"Notes from days off"* appearing in the diary this month. These notes contained a mixture of questions, reminders, about the exhibition *("Just do two waiting areas, an expansion on UKONS poster" "Is there a monitor in radiotherapy?"*), and questions to myself about the research in general *("Shall I call the thesis chasing and waiting?"* "*Started thinking – is the label question the research question??"*).

In terms of project management, the diary had captured and reflected upon how I was sharing the development of the exhibition's spaces, as they began to have been installed by me *("Framed the fine art ones and sent pics with radiotherapy space to group"*). Entries also revealed thoughts about the workshops (*"Been stressing a bit as new workshop approaches – thought maybe use this one to concentrate on digital/track content? Esp. as cannot get on ward due to lockdown?").*

There was one moment where I had considered what I was bringing to the project from my nursing past, or indeed what the project was enabling for me (*"Thought about how satisfying to be using communication skills again from nursing?"*). I'd discussed the project with the nursing research team this month, to which I belong. I had talked about my issues recruiting ("Design or covid?") and I had been encouraged to hear that this was to have been expected (*"S said this is the issue with complex interventions, lots of learning, overcoming challenges"*).

The diary captured my reflecting that this was the time the exhibition became viable (*"Returned to RM for Tues Weds thinking THE SHOW IS GOING UP" "Feel nervous about it going up – final?"*), and my excitement about this (*"Picked up from stores felt good when they read out VisualBeats exhibition - guys seemed interested to hear it was patients work"*). Even at this stage I was making rapid decisions about the installation (*"Walked back from Radiotherapy via Blood Test area and hot,* *chaotic, and rammed – people sat against all walls. Snap decision – get Radiotherapy up first v quiet there!"*).

The following day's diary entries began with the exclamation *"SHOW HAS GONE UP – literally day of 4th workshop!"*. Even though the installation took place in the early morning, before the clinics had opened to patients, I'd been able to capture feedback from passing staff (*"Radiotherapy Aide – used to be illustrator/nurse, likes half done drawing as interesting" "Another Aide can't believe it's a patient, says clearly got talent"*). But also, from these first interactions, thoughts on how the exhibitions' concept was to be communicated (*"Need to be clear its evolving?"*).

I would also capture observations and reflections from the installation (*"used props to get everything sort of aligned, edited one out as can intersperse with posters" "3Ms worked well, foam boards a bit disappointing, bowed" "No lightbulb above start! Will order asap"*). Also, how I'd communicated the launch to the artists involved (*"Messaged PP and told him how I made the vid sent that too obvs" "Messaged PP with image of show said just sorting lighting and audio and said we will discuss next steps - his question was what are next steps - in tonight's call can he make it"*), including those that had not made the initial hang due to illness (*"Messaged PP – she's been ill again, can't take part. Offered to see her today in RM otherwise said will make sure her work is up on 26th when in for radiotherapy"*).

The diary captured how the fourth workshop took place on the day the exhibition was installed. In terms of a *Revelation* from this workshop, I had noted that the PPs talked about themselves as contributing artists at the beginning of the session (*"They didn't introduce themselves as patients!!"*). Overall, my diarised reflections on this fourth workshop had been much more positive than previously (*"Seemed much happier. General positive vibe with me being congratulatory?" "Conversation flowed better with minimal planning - looked at workshop contents on schedule beforehand and sketched some notes" "Felt like a natural close for this tranche"*).

I had consented a new PP before the workshop that day, and we had discussed their interests, which provided some feedback on the newly installed exhibition (*"Talked about CAD (Computer Aided Design) drawing, liked the idea of the exhibition - ages involved, graphic design, NOT about cancer, can add to it/not static"*). I did reflect that, due to the restrictions, it had felt odd to be installing without some of the artists being involved ("to have control over everything and being responsible for every decision –editing – felt weird doing it all myself but things seemed to fall into place") and I acknowledged that some curatorial decisions had been very much my own (*"The I beat it posters* *didn't seem to work downstairs"*). Nevertheless, the PPs were able to assess their content from photographs, and to suggest adjustments including when it became clear one of the mirrored artworks had been placed upside down (*"he wrote back he chuckled when he read that"*) and to contribute further to the video for the Blood Test Waiting Area which was still being developed.

The following day I had begun to reflect on how to better invite the PPs share ownership of the show with the artists (*"All PPs need to have something to go home with – will plan new prints etc around that. May give PP3 the wrapped undamaged items as he is very particular?"* "*This is first time really thought about legacy"*). I was still needing to consider the COVID-19 restrictions however (*"Thought about inviting PP2 to see show but will wait until all up in 2 weeks' time if he's back"*). Although I had put the video together, five artists had contributed content. When I had sent out a final video cut for approval three had got back that same day (*"One liked black and white, another said that's awesome and voice message from another very positive though said wish they could see it"*).

I'd also started to think reflectively about how the show will be promoted by me *("Speak to comms about promotional video/YouTube/podcast"*) and contemplated the possibilities of social media once the digital material was complete (*"Ongoing work with PPs - video issues, YouTube"*). I had been asked by a *VocalBeats* musician if material needed to be suitable for online content and said that was not a priority (*"They asked about swearing - she's angry - I said that's fine. No censoring, this is not a promotional video"*). I'd contacted the hospital's marketing director about promoting the exhibition and had a positive response (*"she said happy to help, will have a think. Amazing"*).

As the printed materials started arriving, the diary had captured my decision making around installing the exhibition in the remailing two spaces (*"Went to get stuff from stores, turned into multiple trips for A3 posters as raised lettering and dog posters arrived. Thinking now get radio done today, rdac and btwa Friday"* "*OK – found missing I Beat It posters in post room"*).

When installing in the two further spaces I had interacted with a patient who had arrived early in the Blood Test Waiting Area (*"lady sitting said is it your work - no patients. Oh yes, I read the poster what's the significance of the dogs - it's her favourite thing. Oh"*). I had sent images to the artists of the new installations (*"I love it"*) and the new video (*"love it. Sorry I didn't see it sooner"*). The installation within the Rapid Diagnostic unit was more fruitful in terms of initial engagement, I had noted (*"Put up exhibition in about 30mins! Nurses J and M said I love it and consented to photo"*).

I had also attended a couple of arts in health events, one an internal Arts Forum meeting at the hospital, and the other an online conference. After the internal event I'd reflected on a heated conversation about losing temporary exhibition space within a canteen area of the hospital (*"Consultant quite forceful about keeping it as exhibition space counts. Prove it I suggested - realising* *isn't that what my research is about!?"*). The external event was about best practices for evaluating arts in health activities, and I had noted in the diary afterwards that the research project did feature those practices (*"Deeper and Richer Data as an Artist Perspective recommendation: they have helped with the exhibition!"*).

Despite these expansive reflective thoughts, the reality of exhibiting in the hospital (and during a COVID-19 pandemic) had returned (*"2hrs mask and hand sanitiser work on the front door. Got a call halfway through to say RDAC exhibition had fallen down! Fixed. Went back to desk via RAD to make sure that hadn't fallen down too!").*

Also, after the initial elation that the exhibition had been installed, I had begun to capture my own and others' reflections about the content, thematically. I'd discussed the emerging exhibition as part of my Confirmation review at the university, and during a supervision session. I'd also begun to reflect on the textual content that made up two artist contributions, with my supervisor's help (*"it's called VisualBeats but it's not very visual"*).

My diary entries were defiant in their tone at this time. Even though I may not have understood the significance of the written and spoken words in the exhibition yet, I needed to defend their inclusion. I had also at this time co-presented with the YSC slides about the exhibition to the hospital's children and PP's clinical leads, which felt more positive *("Presentation went well – lead consultant said "amazing," suggested wider sharing"*). When checking on the installations that day, a patient in the Blood Test space gave more encouraging feedback also (*"you watch, people won't want to go for a blood test now"*).

Towards the end of November, the hospital's social media content had gone live. At that time, COVID-19 was still very much dictating people's activities, so I had been pleased to have this online option for communicating the exhibition in place. It was still a nervous time I reflected (*"Applied for vaccination and saw that Tier 3 research participants have to be remote"*).

5.13 Around workshop five

In the December diary I had recorded and reflected on events around the fifth workshop. This month, I began with the entry *"Busy week – steering group, workshop, confirmation viva."* Towards the end of that week, with the exhibitions up, diary entries were less about facilitating artwork installation, more about reflections on letting the exhibition *Be* ("Feels like should be winding down things a bit, taking stock after this weeks' events") although some challenges remained with regards the display *("Walked round before opening and – as feared – xmas tree in place! Have to laugh. Exchanged messages with PP about this. She's unwell and being transferred for RAD. Said not to worry about workshop later. Said she wants to hear what's discussed"*).

Further liaison with the artists involved continued, with trepidation *("Saw that new PP is on ward still felt bad for seeing this as an opportunity? Looked up when others are next in – one today. Also messaged PP about coming in and having a safe tour of the spaces later. Wondering if them not actually hanging exhibition means they've disengaged? Will see*). It would seem from further visits (see Figure 11 below) and subsequent entries that these fears were unfounded (*"Tuesday was busy with Chelsea valuation but received positive messages from PP2 and PP5 about visits"* "*Afterwards met PP3 – cam3 two hours early so just managed to get video on and tour three areas. He seemed happy in RAD, chatted to a punter. Took couple of photos. Talked about YouTube and feedback. Bought him a cuppa"*). I had reflected more positively later that week (*"Been thinking: Good that J said show was as expected and edgy. Cool they are having own private views"*).

Figure 11 PP visit to VisualBeats in the Radiotherapy waiting area (December) [Diary image]

As we entered the Christmas week, with the COVID-19 restrictions persisting, I had reflected *"Went into Tier 4 on Saturday. Had to rethink all contact for next couple of weeks."* In the diary I'd reflected upon the impact these tightening restrictions may have on an evolving show (*"Worried PP7 will be upset her images aren't going up, as printed and ready, but have had thoughts about adding drawings and/or objects using hooks and lines/poles?? from PP5 too"*). I had begun to propose an end point for installation *("Covid vaccine booked so decided to aim for next Tues for exhibition completion"*).

Setting this installation end deadline seemed to spur reflections around how I may have limited participation (*"Did recruitment end early to allow for [musicians moving to] paeds?"*). Also, as a PP's illness deteriorated which meant installation of an artwork would have been delayed (*"Messaged re* [music making software] *then heard he's been admitted for 2 weeks. Talked about objects for next week. No reply? Try again Monday...? Heard back - having line put in - said maybe lunchtime. I said let me know if don't want visitors"*). Thinking about my own exhibition-making, again the focus became on temporal pressures (*"Surprised how long making labels takes!"*).

In the diary, I had reflected on a visit from a PP at that time (“*Message from PP2 – he was in clinic can he view exhib? Quickly went round checking all ok, saw was less busy so managed to get Mother p works up, last label plus a copy of I beat it. Showed him and dad round – some discussion about spaces, photos, feedback. All agreed people are passing though quick these days. Talked about not doctoring his image for the flyers (they’d all gone!), and summarised next couple of workshops.”* When I had returned to the space after the visit (having earlier in the diary recalling *“...flyers! BTWA”*) to replenish the I Beat It flyers, I recalled “*Sister N came out, one pat there, asked if all ok, she said they’ve had a few complaints*.”

Here was the entry for that episode: “*She said it's had a few complaints as emotive, had some sick people in, if it didn’t say I Beat It would be fine as some haven't. I said does she want it down she said sooner rather than later. Liked the dog. I said I’d get more dog! Pt in waiting area said I wouldn’t like to be sitting here with that waiting for a result, it's in your face. Thanked them for feedback, said I’d been asking for some feedback. Saw sister in corridor offered to take it down straight away – she said yes seemed thankful, so I did. She said I could pick up leaflets from sister’s office – went round and they said they’d been recycled as had some complaints. Despite last time being told all gone?*” I had decided to discuss this in the following workshop.

Around this time, another PP visited the exhibition spaces, which went more smoothly (*“Nurse M in RDAC had met him and said she/we loves this sort of thing”*). Elsewhere, in December, I had noted that *“PP7 had commented in passing on the social media photo but nothing major”*.

5.14 Around workshop six

In the New Year diary, I had recorded and reflected on events around the sixth workshop. Entries began with another update on the persisting COVID-19 disruption (*"Evening, new lockdown announced"*). I had reflected that this may have been influencing artists' ability and capacity to meet and discuss the exhibition (*"Sent PP2 message about seeing video in space later. He declined offer and wanted to get out asap - OK – he replied thanks for your understanding"*). I had also noted that my own ability to dedicate time to the project was being impacted (*"Busy day dealing with arts programme stuff, rather than exhibition. No patient contact"*).

Also, I had reflected on how the new restrictions were impacting the completion of exhibition material, meaning that I needed to make more creative decisions about the spaces (*"should use the stored Mother p poems to do a series? Still might. Had also thought about moving a dog pic up to BTWA...might need some explaining to the artist though?"*) and artworks themselves *("should have brought rasterised image home to PVC varnish? Silly really. PP5 in Friday and can bring objects. Liked miniatures! Messaged him about bringing two drones on Friday – superb"*). Were visits did take place there had been an opportunity to discuss the overall display with the artists (*"Met PP5 after his clinic. Went to RAD and put up the drone. He said area looks bigger, looks quite cool, can't quite believe his drone is on the wall in an art exhibition. I said shows a bit of everyone's personality"*).

I had recalled working on artworks with PP5 over the Christmas period (*"Spent time rastering and messaging PP5 about those and coasters - all I could get printed over xmas. Coasters as miniatures"*). However, with most exhibition material now installed, attention switched to the co-creation of the YouTube video, as an Online Viewing Room (OVR) (*"Looked through Screening Log for appointments coming up – couple today. The rest were all on bad days or far in future – need to rethink!!"*). I had also contemplated the wording that the communications team had proposed for the video (*"Spoke to L re OVR. Talked about why interviewing might not be good in terms of protocol. One or two questions, I told her the label ones. Hers will be about them as creative people?"*).

In terms of organising the artists to contribute to the OVR, most liaison had happened via messages (*"Messaged participants about Tuesday's session with photos of PP5 exhibit (and asked about* [PP5 dog] *op!). PP4 messaged back that he needs to arrange dad in advance so reassured him he could film his piece at home. He replied positively"*). Despite last minute efforts to gather the material requested by the comms team (*"Track arrived! I forwarded it to L and R – congratulated [VocalBeats musician] and PP2"*) the OVR filming went ahead as planned this month. I had noted in the diary

"Went really well – one hour and spaces behaved! Updated R on material – said could get staff comments if needed. Did not seem surprised participants wanted to approach it creatively."

In the second half of January my attention had turned to organising Workshop 6. With the COVID-19 restrictions in place, the initial exchanges were to ascertain a suitable location for the session (*"Messaged YSC to see if anyone inpatient (no reply) as wanted to stay off site if poss"*). After it was agreed to hold the session online, reflections turned to establishing which of the artists may be free to join and drawing up contingencies accordingly (*"Was worried only heard from PP4 (planning to just share his feedback if only participant), then PP2 said maybe join/maybe not say much, then PP6 messaged to say no problem so let's see!"*). These arrangements had continued the day of the workshop (*"YSC had also messaged back to say PP5 was on ward, couldn't say if safe for me to go in as may be COVID-19 risk and in a room. Said she'd call me back but didn't, asked again 4hrs later and she suggested ring ward. Not easy to do from outside – told her couldn't get through. Big fail really! Got a message from PP2 just beforehand to say just leaving hosp/driving home so can't join workshop said sorry but too late to change time.*)"

The workshop had gone ahead, and my initial reflective diary entry afterwards had been "*First one I quite enjoyed as much as I could worried about technical issues. Explored lots of avenues including art therapy, friendship, terminal illness. Much clearer thoughts*." In my workshop notes I had once again reflected on the vagueness of my facilitation, which could have been thought of as conceptualisation, (*"Vague about relationship with VocalBeats – could have been clearer about research being within the programme" "Vague later about the OVR - is being vague good/productive/creative??"*).

I had reflected on how I had found a space in my workshop facilitation to observe the overall flow and content, as it happened (*"Comfortable with silence/spaces for thought such as diff between music therapy and VB" "Interesting they talk about what they want to portray"*). I had also identified areas for improvement (*"Would have been good to share PP2s image I was talking about to get more feedback" "Could have explored the idea in more public spaces?"*). Also, I noted that I had arranged to meet the I Beat It artist, as we had discussed feedback about that in the workshop and they had not been present. I said:

"Meeting with PP2 in clinic. Gave copies of slides and discussed I beat It versus his positive feedback. Seemed reassured – discussed spirit of the piece and mis construal, how words introduce messaging/activism? Talked about hospital versus gallery. Offered to show him transcript also. Said he can come to the next workshop."

5.15 Around workshop seven

In February's diary I had recorded and reflected u[on events around the seventh and final workshop, and the de-installing of the exhibition. During this time, I'd been approached by another patient regarding the potential purchase of an artwork. I arranged a call with PP3 to discuss this who felt this was somehow an inconvenience of me (*"Was very apologetic and pleased"*).

At this time, the exhibition began to be de-installed (*"TOOK DOWN BTWA show at 0730!"*). Accordingly, I had arranged with the artists to collect work when they were next on-site ("*Snowing – on bus coming in as PP4 coming to take piece from RDAC. 3 PPs are in today. Messaged them all. One is not coming due to the weather"*). When the artists did arrive (Figure 12 below), I captured their responses to the show as for one or two it was the first time seeing their artworks in situ due to the COVID-19 restrictions (*"PP4's dad did call me when they were done at 2pm, took to RDAC for photo and removed his piece, bagged up. He touched it, seemed happy"*).

Figure 12 PP visit to VisualBeats in the Rapid diagnostic unit corridor (February) [Diary image]

In terms of my own responses to the de-installation, the diary had captured *"Took down RDAC felt strange as remembered putting it up way back...?"* and *"Feels weird with VB stuff off the wall and in a pile!"* I had also captured that the YSC had begun preparing the artists for next steps after the exhibition, including providing information on new art and music projects planned (*"Asked YSC to send a group message about this and the new projects, which she did yesterday!"*). I had then noted that PP3 had enquired further about one project (*"Returned image boards and discussed new logo project – very interested so let YSC know"*).

The final workshop took place mid-month, with four PPs in attendance. I had reflected in the diary *"All very positive. Felt like exhibition is important, link back to music programme less so."* I noted that, in terms of my facilitation, I had been *"Good at making sure all participants get a chance to speak on each subject. I used a miracle question!"* As per my reflection on previous workshops, I noted things I could have done better (*"Should I have made more of an effort to describe the artworks in the video for those with visual impairment?"*).

On February 23rd I had noted in the diary, referring to the COVID-19 restrictions, (*"End of Lockdown announced last night"*). At that time, I had recorded messaging the artists thanking them for participating and saying I will be in touch regarding the research publication.

5.16 Beyond workshop seven

In this section, I have recreated an autoethnographically-inspired diarised account of I personally took part in exhibition-making as a HAPM facilitating the VisualBeats project. This account described the curatorial self-observation and self-reflection that came from facilitating the project.

On reflection, I feel that that the diary had successfully captured “curatorial tensions, mistakes, revelations, decisions, and compromises” from my facilitation (Puwar & Sharma, 2012), and Schön’s framework may be helpful in exploring these as techniques for facilitating the co-curating (Schön, 1983 p18).

Around workshop one I had reflected around applying my known techniques to managing conflicting priorities. At this time, I was approaching my facilitation of VisualBeats, and the diary, against the backdrop of my increasing appreciation of *being curatorial*, from accessing the recommended reading list of the university’s Winchester School of Art (WSA) MA in contemporary curating practice. Within that literature, which was discussed with my supervisor as MA course lead, behaving in a curatorial way meant establishing a presence that aimed to create a degree of friction and push innovative ideas through “relationships between objects, people, places, ideas” (Lind, 2021).

In terms of beginning to explore my facilitation diary thematically, reflecting beyond does generate some initial thoughts. Around workshop two, for example, I am concerned with my sociality. Around workshop three I was concerned with my ability to coordinate, communicate, and to deliver the project successfully. Around workshop four, the reader may agree, I had perhaps begun to find my confidence in project managing the collaborations and a successful exhibition overall. Around project five I was concerned, and reflected upon, issues around the *I Beat It* display. My entries had captured me feeling frustrated and nervous about the tensions that had been created. Finally, around workshops six and seven, I reflected on what may have been my more confident curatorial facilitation process as VisualBeats was de-installed and ended.

Overall, then, this reflective diary to capture “tensions, mistakes, revelations, decisions, and compromises” from my curatorial practice (Puwar & Sharma, 2012) did, I hope the reader will agree, reveal a pattern of largely reflexive and supportive facilitation practices. From time to time, these revelations did also happen in real-time and allowed for the scaffolding of a more *professional* curatorial practice with reflection and new understandings (Engin, 2011). These topics will be discussed in more detail below.

That said, perceived negative participant experiences captured such as PP’s feedback that there was a lack of direction around the exhibition brief, and audience feedback that there was lack of consideration for those with terminal illness, may have been reflected upon as care-less facilitation practices also. Overall, and linking back to concepts introduced earlier in this thesis, the diary entries have enabled a reflective consideration of my personal assumptions, values, and beliefs, beyond facilitation.

It is necessary to reflect on how the facilitating captured in the diary, and discussed here, may have affected those taking part, including the PPs and VisualBeats audience. Indeed, *functioning* curatorially in such a critical way (Gaitan, 2013, Martinez, 2013), has meant attending to others' visibility and voice (as agency), and being open to confronting hegemonies, hierarchies, and divisions of power (Albano, 2018, Smith, 2020, O'Neill, 2012). Dr Berit Fischer has since described being curatorially critical as allowing a shift to take place where a passive audience can become empowered with agency and "response-ability" (Fischer, 2022). Thinking back to my earlier reviews, when all four articles lacked a clear conceptual definition of curating (or co-curating), inclusion of this *criticality* may be helpful.

In the next chapter I explore the VisualBeats exhibition and its displays. I also explore the audience's and my own responses (and response-ability) to it, before reflecting beyond these findings. In my final stage of transcription and reflection I create an autoethnographically-inspired account of how people took part in encountering the VisualBeats exhibition, as an audience. My account includes material from the VisualBeats exhibition, its labels, and other paratextual features. Again, the intention is to invite the reader to encounter (and explore) the exhibition from their own point of view.

VisualBeats as a temporary exhibition was installed between November 2020 and February 2021 in three public locations at The Royal Marsden Hospital in Sutton. I had gathered images as part of my diary and had also gathered perceptions and responses from the audience, as spoken feedback I had received, emails I'd been sent, and social media posts I'd viewed, during this period.

The VisualBeats exhibition was displayed in three areas of the hospital: the radiotherapy waiting area, the blood test waiting room, and the rapid diagnostic unit corridor. The exhibition was available in varying formats across those three spaces. These display spaces were not fully open to the public as visitors were not usually allowed to accompany patients during this time, due to the COVID-19 pandemic. However, even during the pandemic, these spaces were open and were full of patients and staff between 8am and 5pm every weekday.

Ambient noise did not usually feature in the display spaces, which were bustling but calm, with conversation minimal except between staff and those waiting for their appointments. Information on the seven contributing artists and their work was made available through A4 and A5 white labelling with black font, as part of the display. Whilst hung at eye level, the display varied in terms of installation, with one artists' work interspersed with another's in various ways at each location. The exhibition installation (or "hang") was continuous within the wall space and in one location (the rapid access diagnostic unit) it spread to an opposite wall within the corridor. In one location (the blood test waiting room) exhibition material was included alongside a temporary display of patient information, unrelated to VisualBeats.

Chairs for patients to wait were placed by unit staff in the exhibition space and stickers on the floor suggested their distancing (due to the pandemic). These were sometimes moved by those in the space and at times the patients were sitting with their backs to the display, occasionally restricting access to the works and labels. Before, during and after images of all three display spaces are shown below.

5.17 Display one

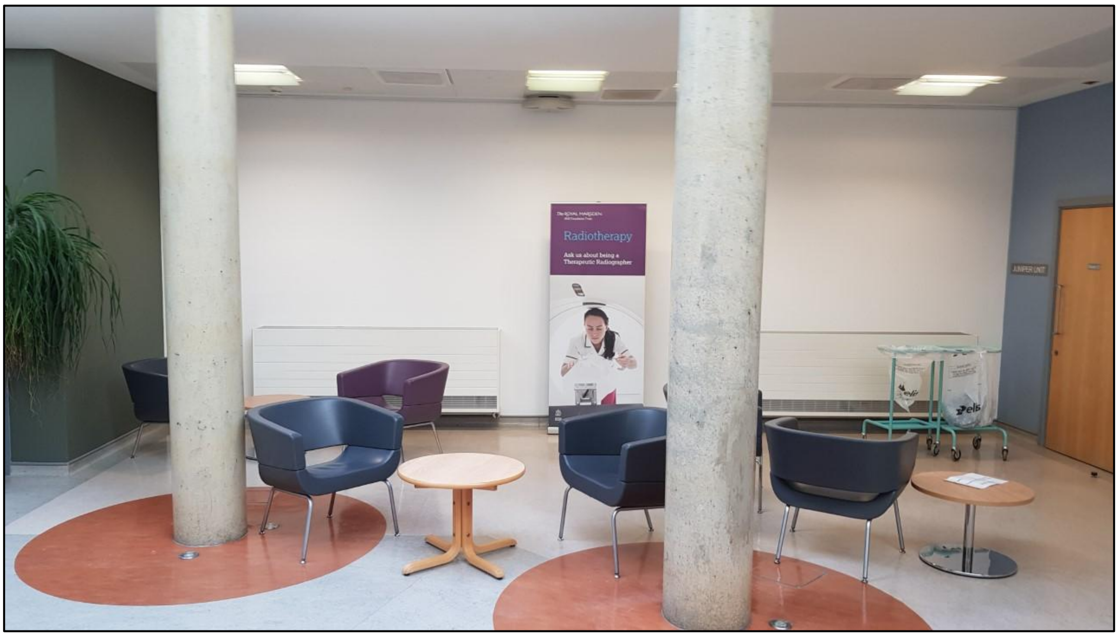


Figure 13 Radiotherapy waiting area before VisualBeats [Diary image]

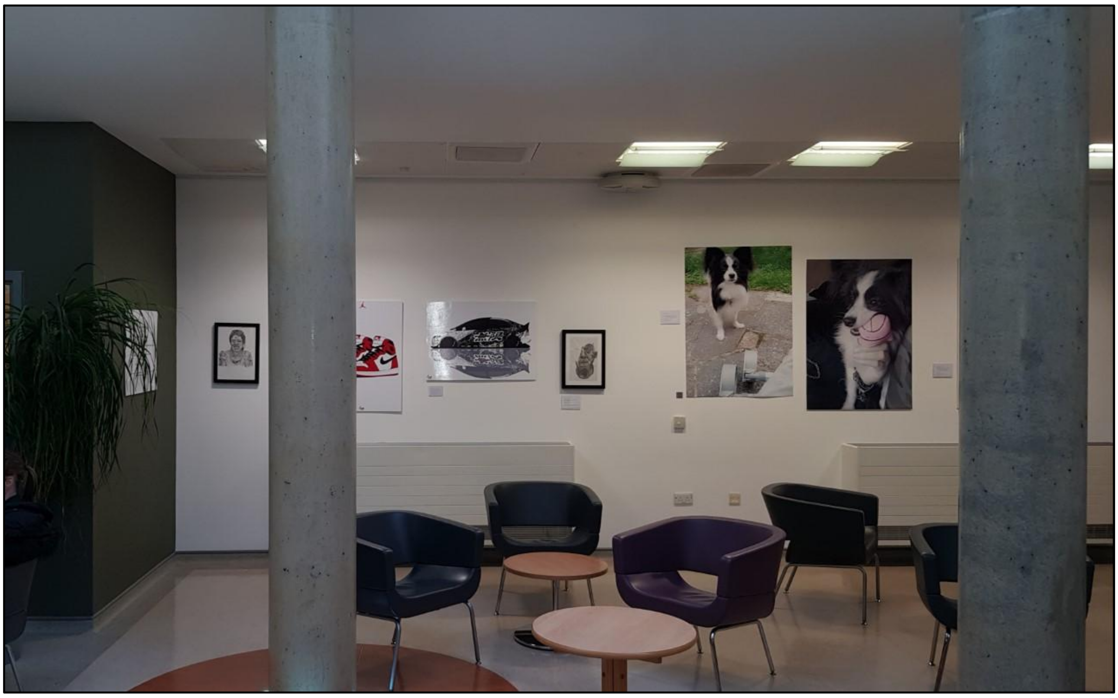


Figure 14 Radiotherapy waiting area VisualBeats (front left view) [Diary image]

Figure 15 Radiotherapy waiting area VisualBeats (left gallery view) [Diary image]

Figure 16 Radiotherapy waiting area VisualBeats (full gallery view) [Diary image]

Figure 17 Radiotherapy waiting area VisualBeats (wide view) [Diary image]

5.18 Display two

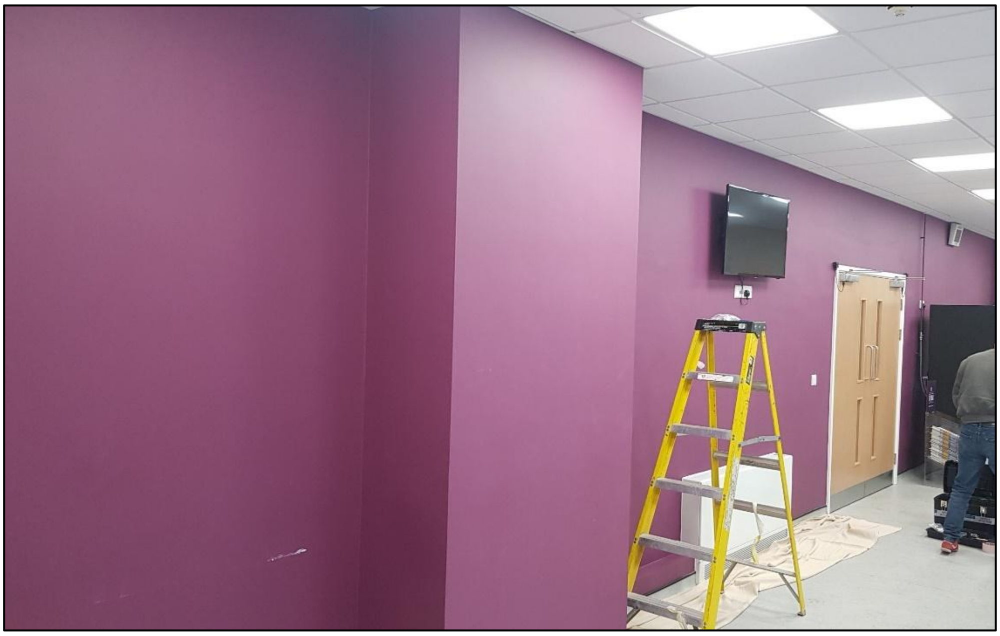


Figure 18 Blood test waiting room before VisualBeats [Diary image]

Figure 19 Blood test waiting room VisualBeats (front installation view) [Diary image]

Figure 20 Blood test waiting room VisualBeats (left installation view) [Diary image]

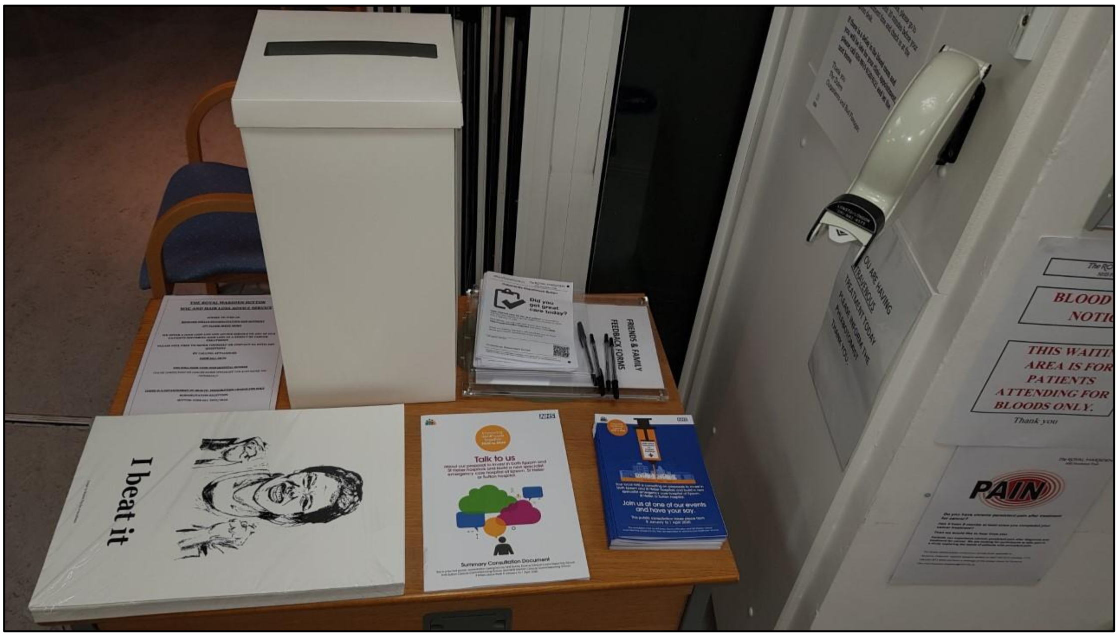


Figure 21 Blood test waiting room VisualBeats flyers installed with other patient information [Diary image]

5.19 Display three

Figure 22 Rapid diagnostic unit corridor before VisualBeats [Diary image]

Figure 23 Rapid diagnostic unit corridor VisualBeats (left installation view) [Diary image]

Figure 24 Rapid diagnostic unit corridor VisualBeats (right installation view) [Diary image]

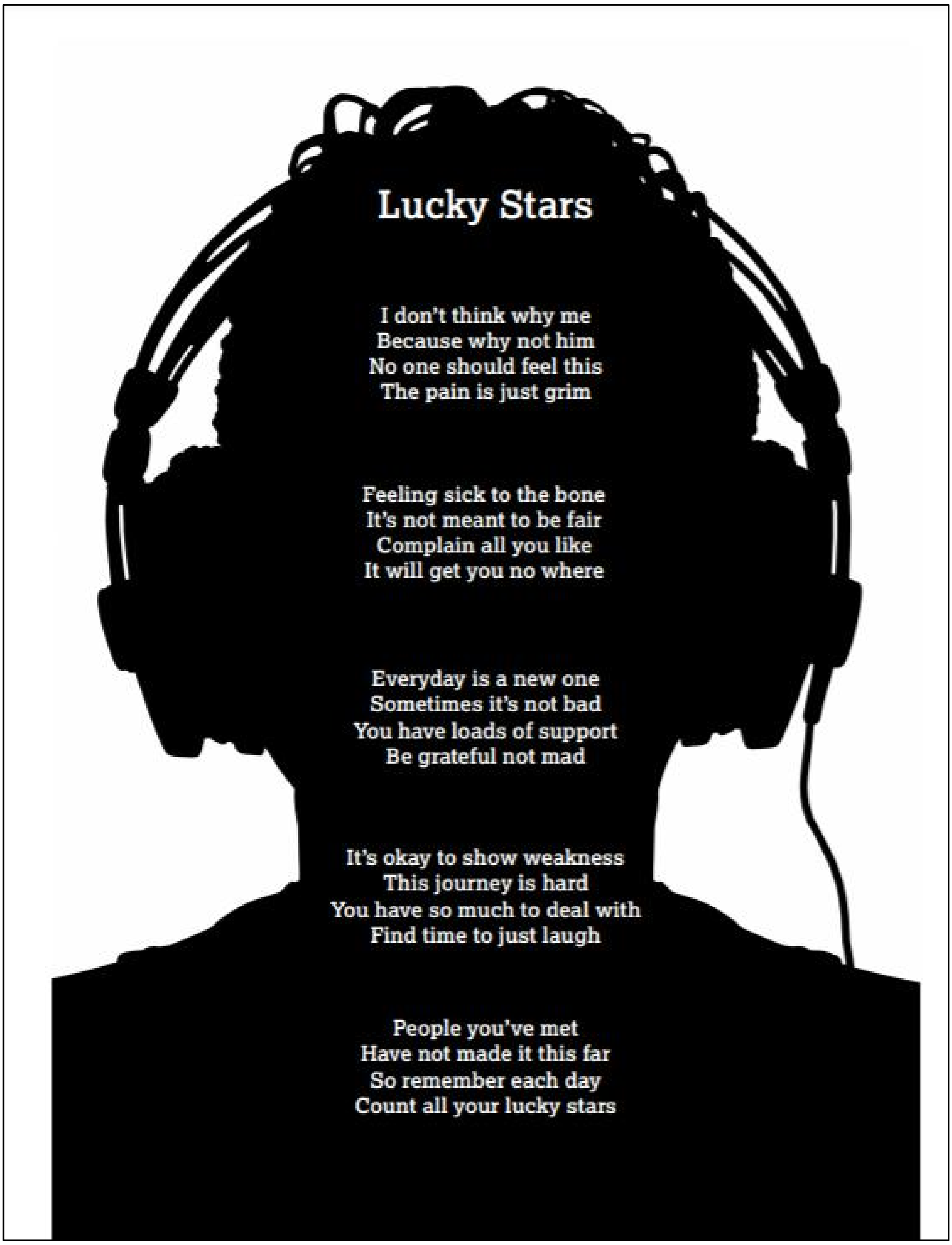
Figure 25 Rapid diagnostic unit corridor VisualBeats (opposite wall view) [Diary image]

5.20 Artworks

A dozen artworks had made up the VisualBeats exhibition. Each artist’s artworks will now be described alongside images of those artworks.

PP6’s Lucky Stars, Mother and Succeed were three printed lyrical poems using Georgia font on A3 paper within a black image of a head, wearing headphones. Each was displayed with an acrylic glaze (glass was prohibited) and in black wooden frames. Lucky Stars (Figure 26 below) began by with the inner conversation of someone experiencing being *ill* and soon turns to words of encouragement, for an unknown audience. Describing pain and sickness, it was easy to assume PP6 had been talking about cancer treatment, but this was not made explicit by the artist. The message was one of keeping positive, acceptance and resilience.

Mother (Figure 27 below) was a much more personal encounter in which PP6 described a relationship with a mother. It describes past pains, and current cancer. It ended by suggesting this public declaration of fondness and gratitude may be the last. Finally, in Succeed (Figure 28 below) PP6 was perhaps communicating with a wider audience. By admitting defeat, being at a lowest point, PP6 also proclaimed a strategy for a brighter future in which success is the only option available.



Lucky Stars

I don't think why me
Because why not him
No one should feel this
The pain is just grim

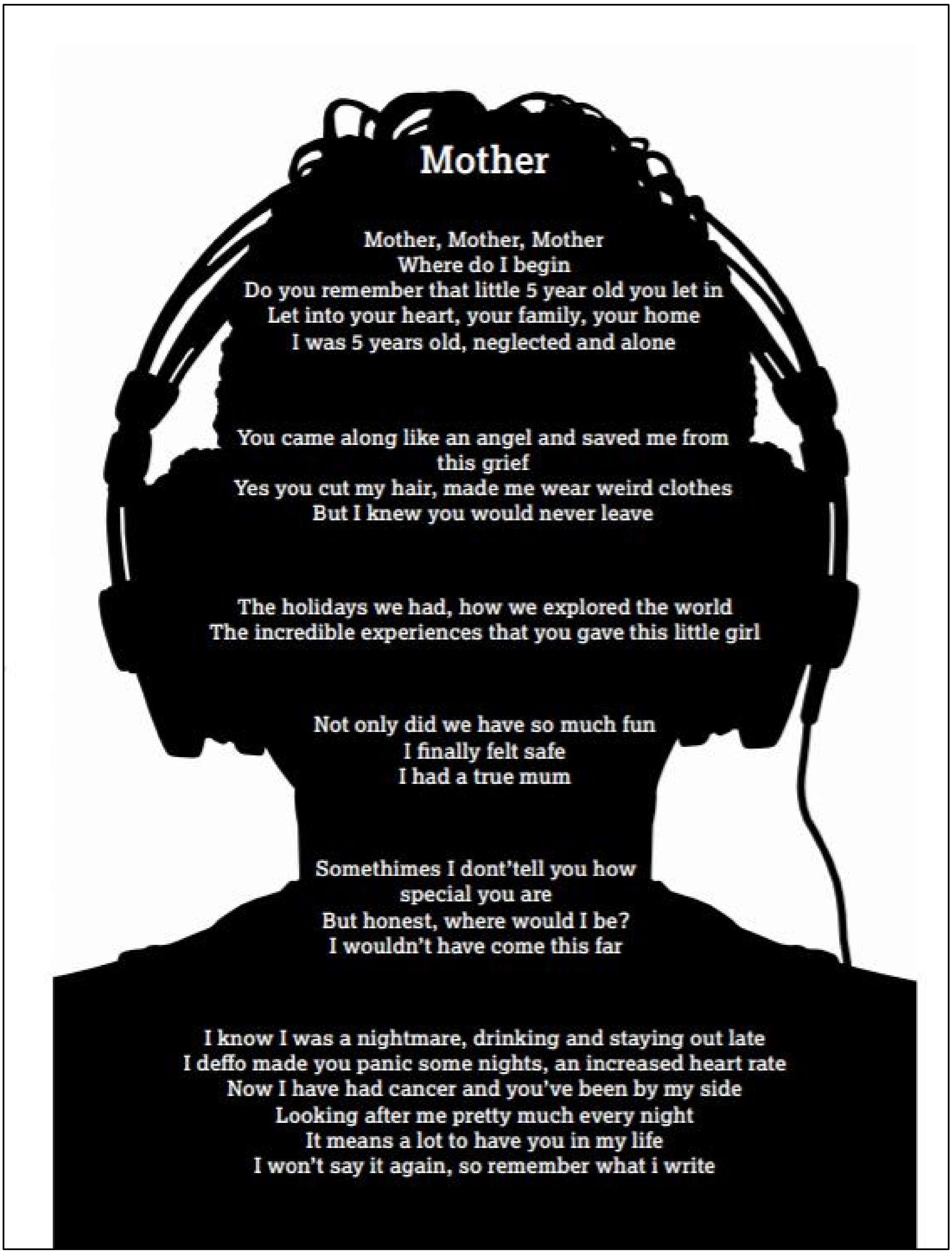
Feeling sick to the bone
It's not meant to be fair
Complain all you like
It will get you no where

Everyday is a new one
Sometimes it's not bad
You have loads of support
Be grateful not mad

It's okay to show weakness
This journey is hard
You have so much to deal with
Find time to just laugh

People you've met
Have not made it this far
So remember each day
Count all your lucky stars

Figure 26 "Lucky Stars" by PP6



Mother

Mother, Mother, Mother
Where do I begin
Do you remember that little 5 year old you let in
Let into your heart, your family, your home
I was 5 years old, neglected and alone

You came along like an angel and saved me from this grief
Yes you cut my hair, made me wear weird clothes
But I knew you would never leave

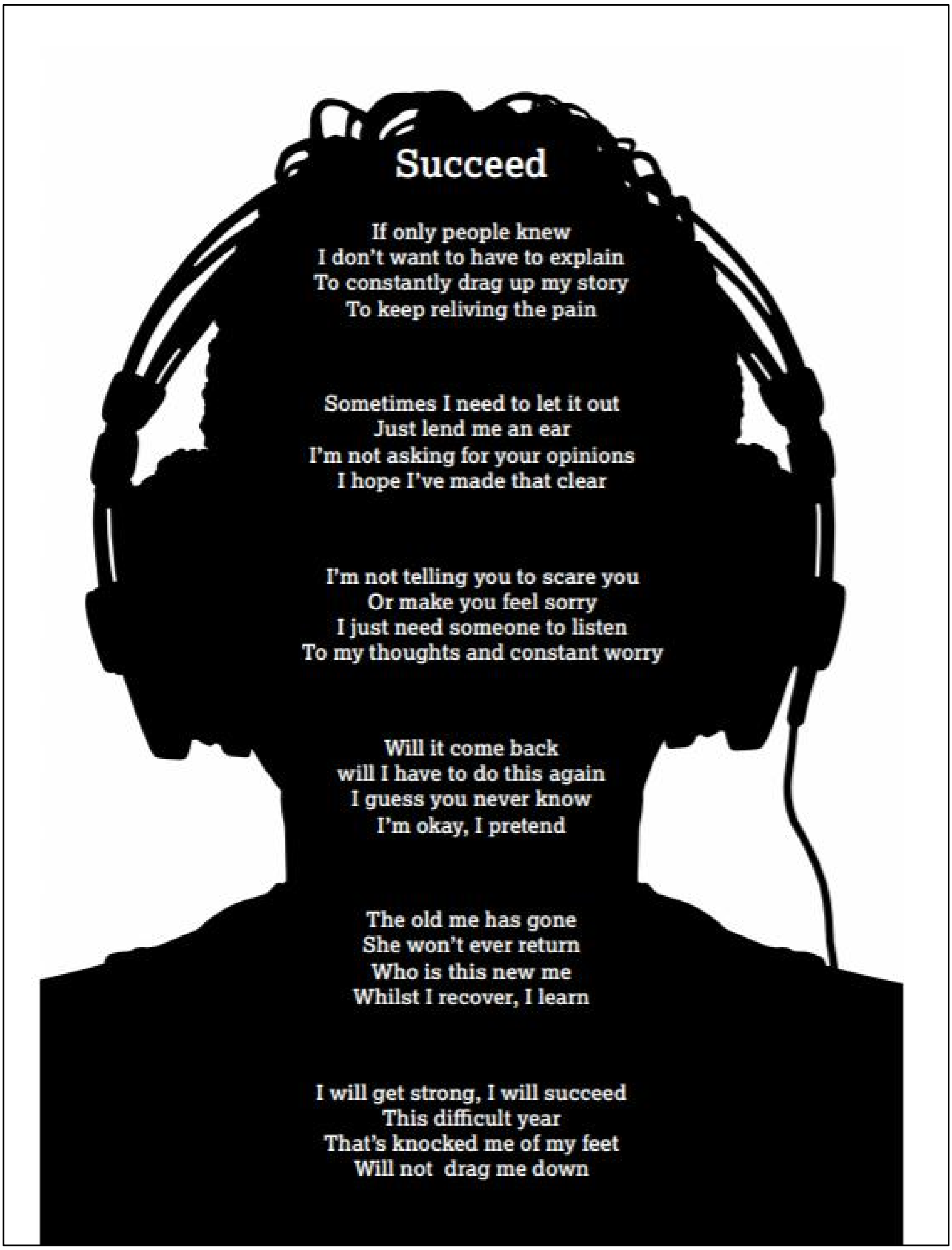
The holidays we had, how we explored the world
The incredible experiences that you gave this little girl

Not only did we have so much fun
I finally felt safe
I had a true mum

Somethimes I dont’tell you how special you are
But honest, where would I be?
I wouldn’t have come this far

I know I was a nightmare, drinking and staying out late
I deffo made you panic some nights, an increased heart rate
Now I have had cancer and you’ve been by my side
Looking after me pretty much every night
It means a lot to have you in my life
I won’t say it again, so remember what i write

Figure 27 “Mother” by PP6



Succeed

If only people knew
I don’t want to have to explain
To constantly drag up my story
To keep reliving the pain

Sometimes I need to let it out
Just lend me an ear
I’m not asking for your opinions
I hope I’ve made that clear

I’m not telling you to scare you
Or make you feel sorry
I just need someone to listen
To my thoughts and constant worry

Will it come back
will I have to do this again
I guess you never know
I’m okay, I pretend

The old me has gone
She won’t ever return
Who is this new me
Whilst I recover, I learn

I will get strong, I will succeed
This difficult year
That’s knocked me of my feet
Will not drag me down

Figure 28 “Succeed” by PP6

PP2’s Untitled 1, 2 and 3 were a series of three pencil drawings on paper, again acrylic glazed in black frames. Whereas the images were untitled, they were distinctive in their variation. The first (Figure 29 below) showed a semi-completed drawing of a moustachioed gentleman, with an expression that is hard to interpret. It was perhaps somewhere between surprise, wonderment, confusion, anger even.

The second (Figure 30 below), completed similarly, showed a young adult in a state of heightened emotion. With their raised hands and clenched fists, it was easier to interpret this as a portrait of defiance (though this was influenced by the I Beat It series – see below). Again, the likeness was assumed by the audience in the intricate detail of the drawing. The mark-making, shading, and smudging all added to the impression that the drawings were intended to convey close diligence of the real-time sitter (or photograph subject – it is unclear), and their emotions.

The third image (Figure 31 below) was a representation of the easily recognisable face of Simon Pegg. Indeed, this leads the audience to assume that this at least may have originated with a photograph of the UK actor-comedian. Again, the emotion captured so clearly in the head and shoulder drawing was difficult to interpret. It looked more aggressive than the preceding two, which was at odds with the public persona of the comedian. No clue to the portraits chosen, their significance, or provenance, was provided.

Figure 29 “Untitled 3” by PP2

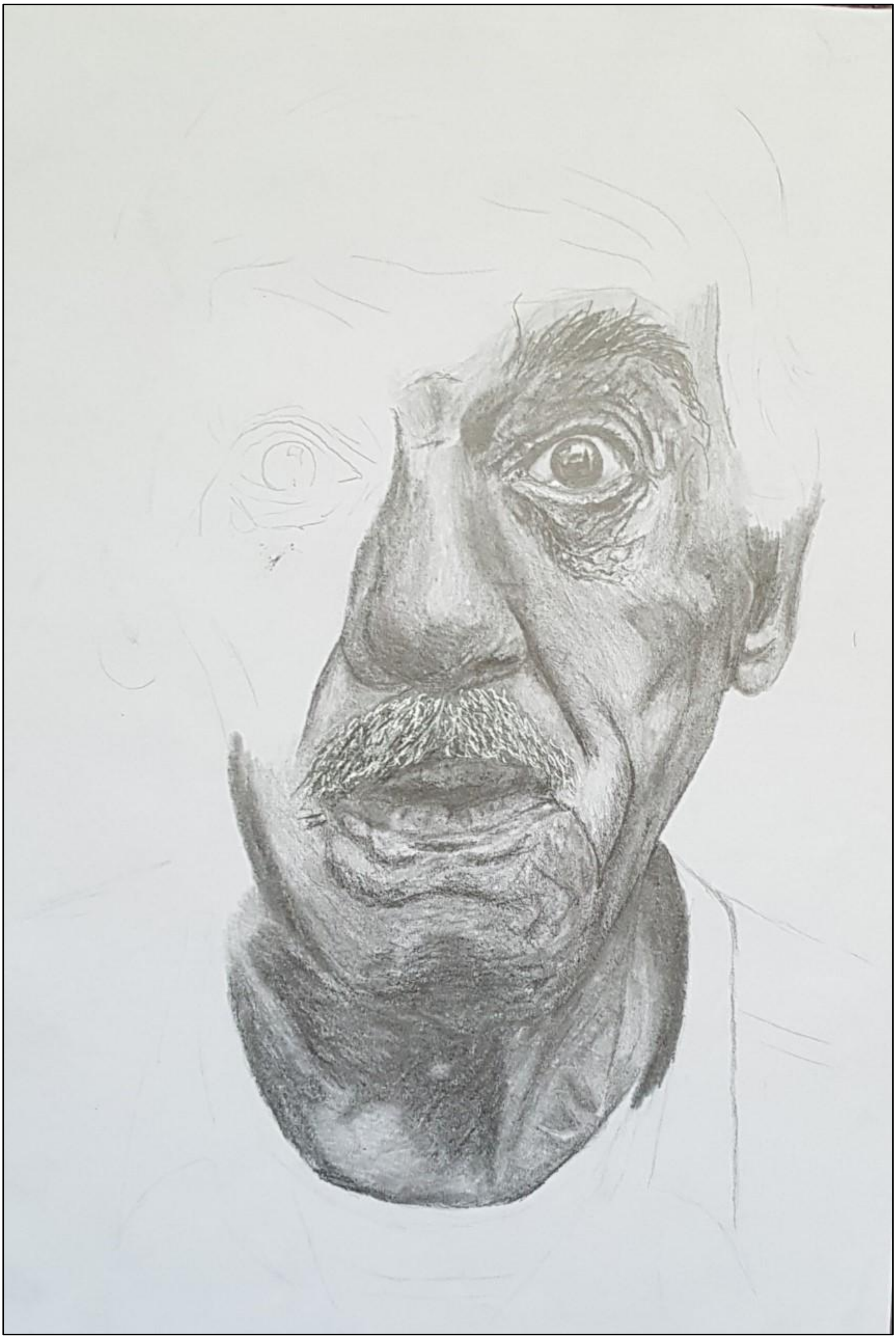


Figure 30 “Untitled 2” by PP2

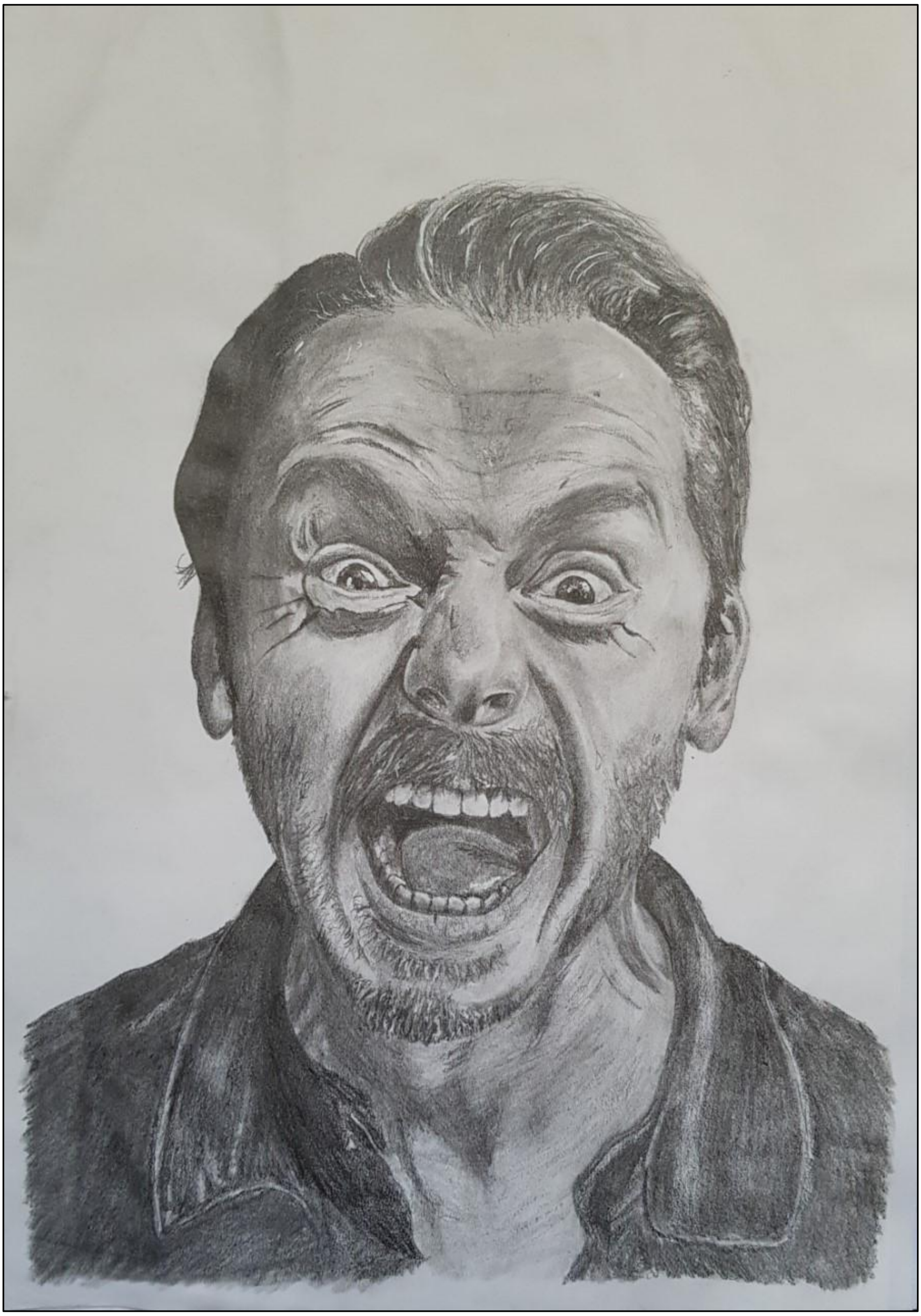


Figure 31 “Untitled 1” by PP2

I Beat It was a series of two hundred A4 gloss print flyers that were both available for the assembled audience to take away (as a loose pile alongside other patient information) and displayed in groups on the aubergine purple gallery waiting room wall in the Blood Test Waiting Area only. Using a highly graphic printed image from the series described above, I Beat It (Figure 32 below) also featured those words in bold print, leaving little in the way of imagination when interpreting the pieces, the message of each was enhanced by the display of multiples, in the space.

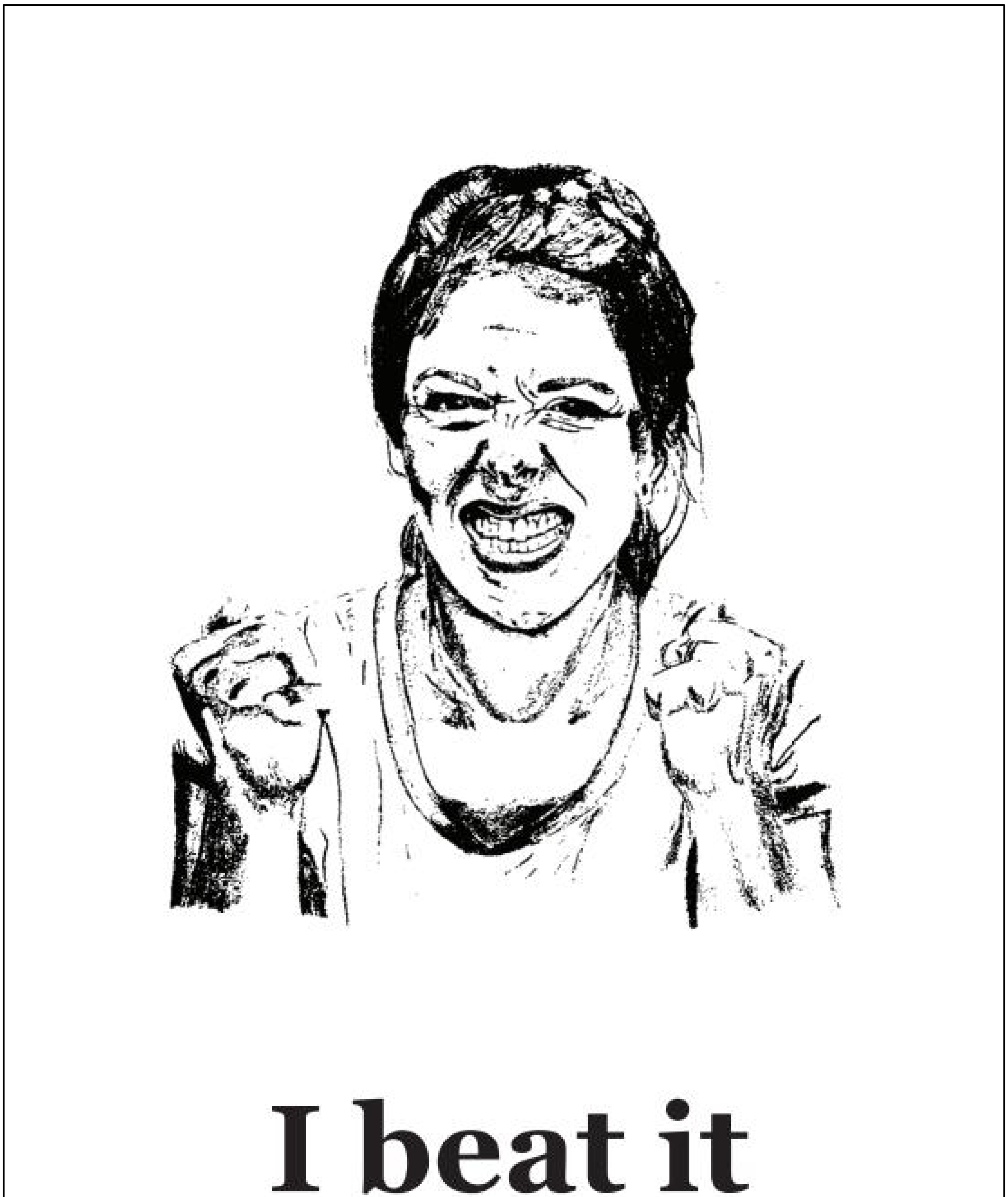
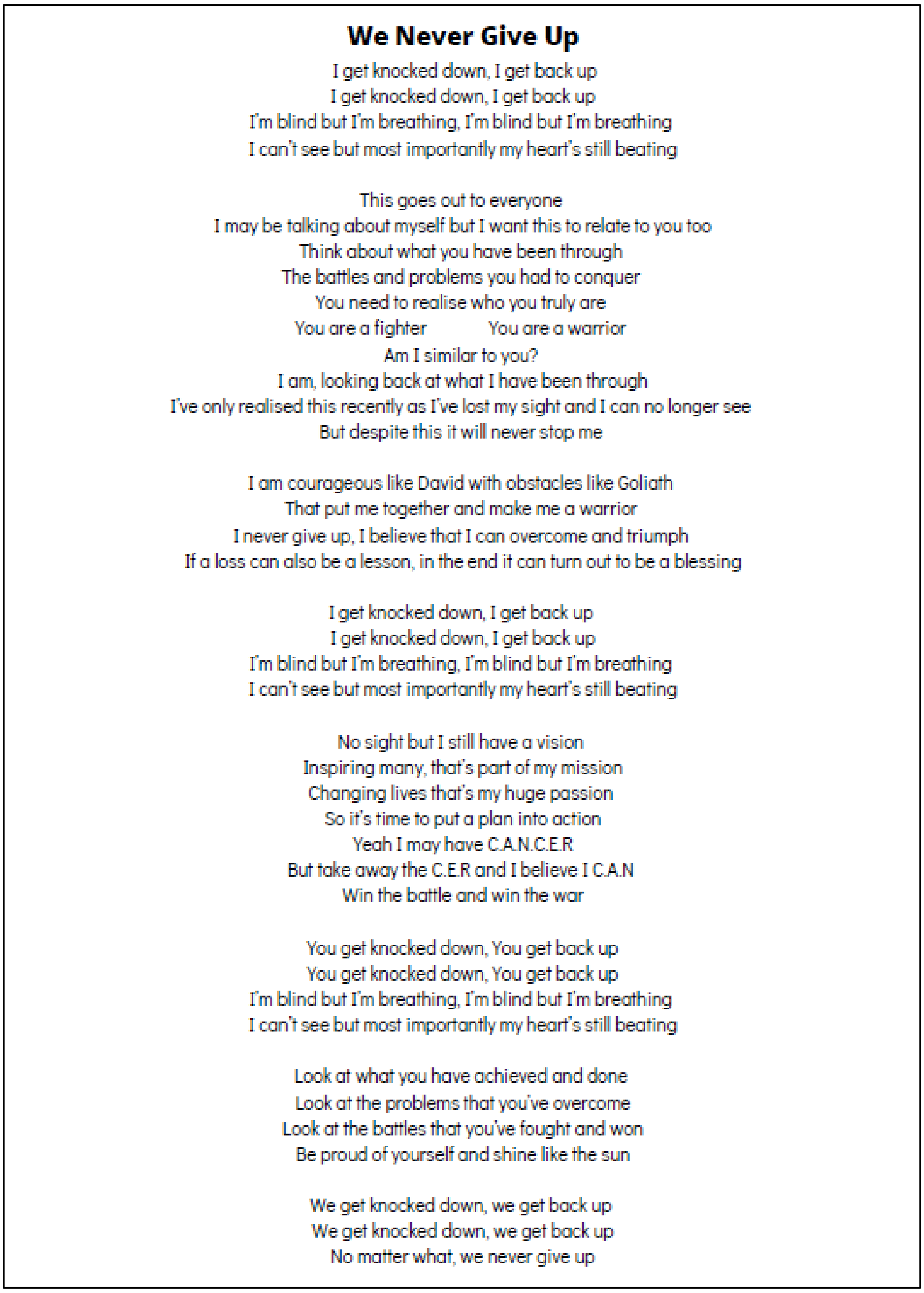


Figure 32 “I Beat It” by PP2

PP4's We Never Give Up was an A0 plastic tablet inscribed with raised black printed script. The scale and weight of the display enabled the content to be easily read. The scale and weight of the words become clear as soon as they had begun to have been understood by the viewer. We Never Give Up (Figure 33, below), which suggested a group endeavour, was instead a lyrical description of personal illness experience, advice, support, encouragement, and appeal. The influence of cancer on these features was made starkly apparent by the artist as it was spelled out letter by letter. The size and scale of the encounter, plus this time attempting to understand the significance of the raised, braille-like lettering, was itself a rite of passage.



We Never Give Up

I get knocked down, I get back up
I get knocked down, I get back up
I'm blind but I'm breathing, I'm blind but I'm breathing
I can't see but most importantly my heart's still beating

This goes out to everyone
I may be talking about myself but I want this to relate to you too
Think about what you have been through
The battles and problems you had to conquer
You need to realise who you truly are
You are a fighter   You are a warrior
Am I similar to you?
I am, looking back at what I have been through
I've only realised this recently as I've lost my sight and I can no longer see
But despite this it will never stop me

I am courageous like David with obstacles like Goliath
That put me together and make me a warrior
I never give up, I believe that I can overcome and triumph
If a loss can also be a lesson, in the end it can turn out to be a blessing

I get knocked down, I get back up
I get knocked down, I get back up
I'm blind but I'm breathing, I'm blind but I'm breathing
I can't see but most importantly my heart's still beating

No sight but I still have a vision
Inspiring many, that's part of my mission
Changing lives that's my huge passion
So it's time to put a plan into action
Yeah I may have C.A.N.C.E.R
But take away the C.E.R and I believe I C.A.N
Win the battle and win the war

You get knocked down, You get back up
You get knocked down, You get back up
I'm blind but I'm breathing, I'm blind but I'm breathing
I can't see but most importantly my heart's still beating

Look at what you have achieved and done
Look at the problems that you've overcome
Look at the battles that you've fought and won
Be proud of yourself and shine like the sun

We get knocked down, we get back up
We get knocked down, we get back up
No matter what, we never give up

Figure 33 "We Never Give Up" by PP5

PP5's contribution Untitled (Figure 34 below) was a built drone with images stickered onto its body. Whilst aesthetically consistent with the red, black, and white hues used in the VisualBeats exhibition displays, Untitled stood out in terms of its manufacture.

By featuring a working drone, built by PP5, the audience was encouraged to think beyond the exhibition space to where this flight of fancy may have occurred, and even why. The significance of the object as both unpretentious and industrious, found, was subtle but striking. The viewer could connect the drone with aerial footage elsewhere in the exhibition.

Figure 34 “Untitled” by PP5 [Diary image]

PP3’s Mugen Splash (Figure 35 below) and Crimson Icon (Figure 36 below) were a pair of digital drawings printed on almost A1 size portrait foam board. They were striking by their graphic content, clarity of line and vibrant use of shades and hues. Both were digitally and cryptically signed by the artist “LM” (being explained in the video piece below as the alias “Livery Magic”), and featured branding within the main images, and as icons surrounding them.

Figure 35 “Mugen Splash” by PP3

Figure 36 “Crimson Icon” by PP3

Untitled 1, 2, 3 were a series of three photographs by PP7 printed as A1 and A2 posters with a thick plastic coating. They featured colour vignettes of the photographer’s life, as influenced, and impacted by, cancer, though again this was not made explicit by the artist (save for the glimpse of crutches). A central feature of the images was a pet dog, of whom the documenter was visibly fond of and affectionate to.

In Untitled 1 (Figure 37 below) the dog was shown by the artist in a private garden (looking directly at the photographer), in Untitled 2 (Figure 38 below) during bath time (perhaps wanting to end the bathing experience) and in Untitled 3 (Figure 39 below) being stroked by a human hand with a pink ball in its mouth. The images were direct, suggesting having been taken on a mobile phone, with minimal personal visual prompts save the crutches and jewellery of the dog handler.

Figure 37 “Untitled 2” by PP7

Figure 38 “Untitled 1” by PP7

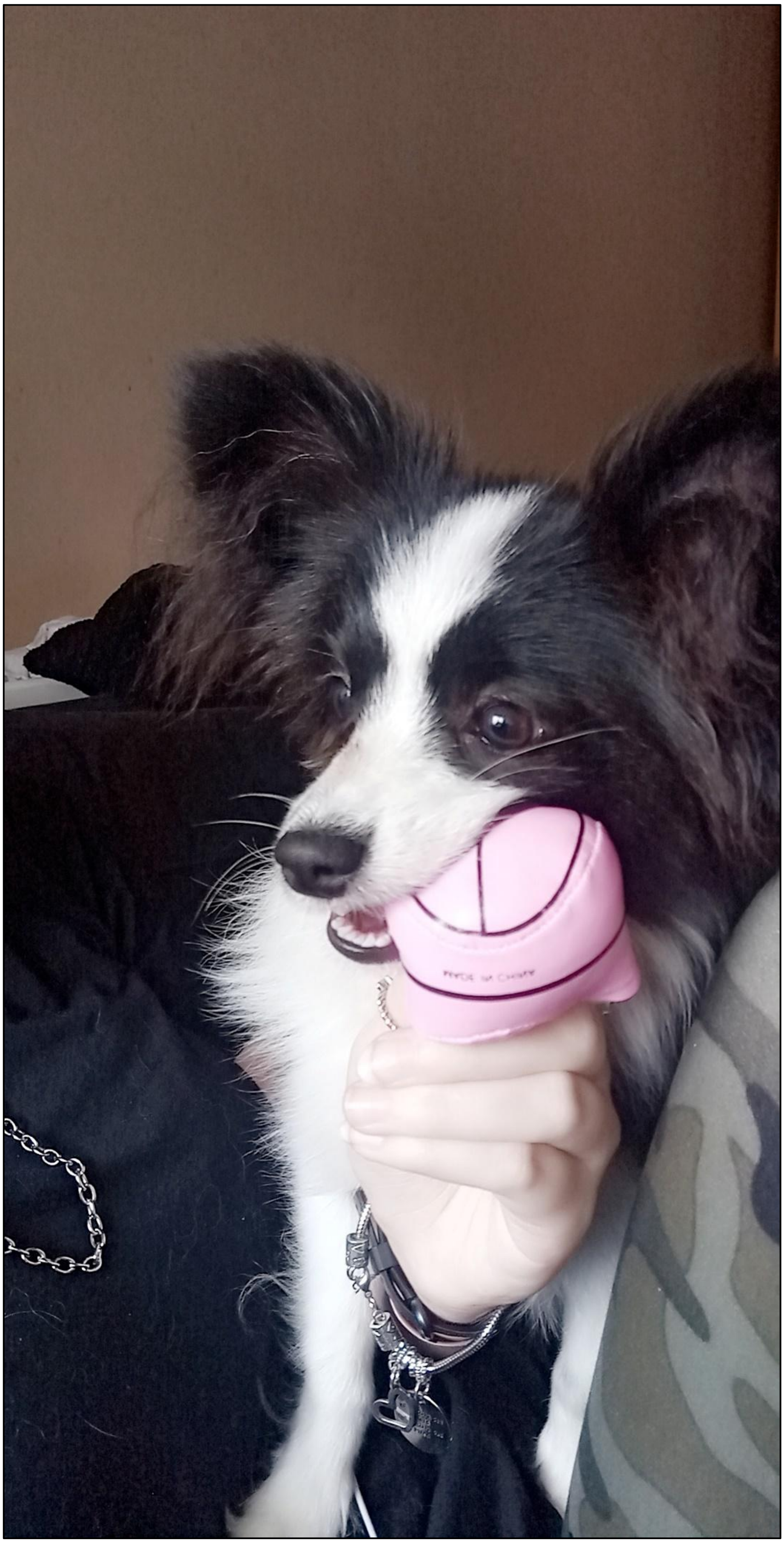


Figure 39 “Untitled 3” by PP7

On the screen in the Blood Test Waiting Area only was a looped four-minute monochrome video that began with a moving, black, and white image of a Mazda 3 (afterwards identified by the artist PP3 as Mario Battle – Figure 40 below).

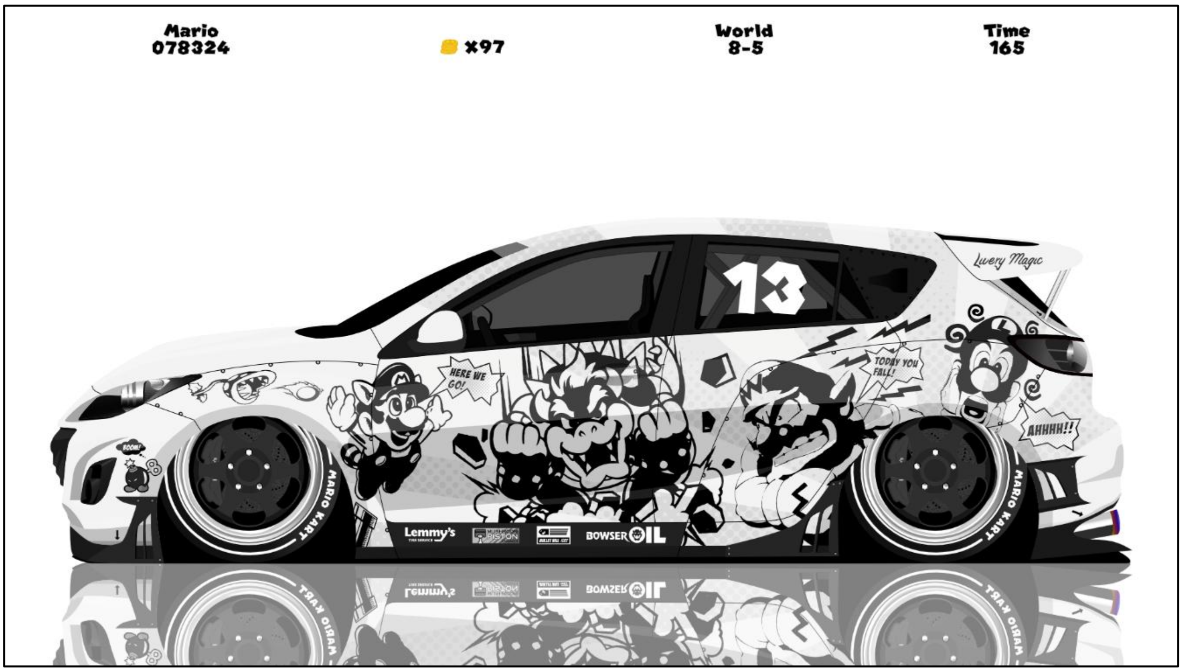


Figure 40 “Mario Battle” by PP3

Following this a stop motion video showed the development of PP2’s face image (displayed elsewhere in the exhibition and used in the I Beat It series of prints. The video, a collaborative undertaking, then featured slow motion colour clips by PP7 of rodent pets in cages, playing on the wheels. PP4 read out excerpts from his Never Give Up lyrical poem as it was displayed.

The video finished with PP7 playing a section of piano music, accompanied by monochrome footage of keyboard playing on its side (Figure 41 below). Next to the video screen, and the video which ended with the hashtag #visualbeats, a label identified the music track as Reaching Millions by PP1 here as “(alias: Apollo)”.

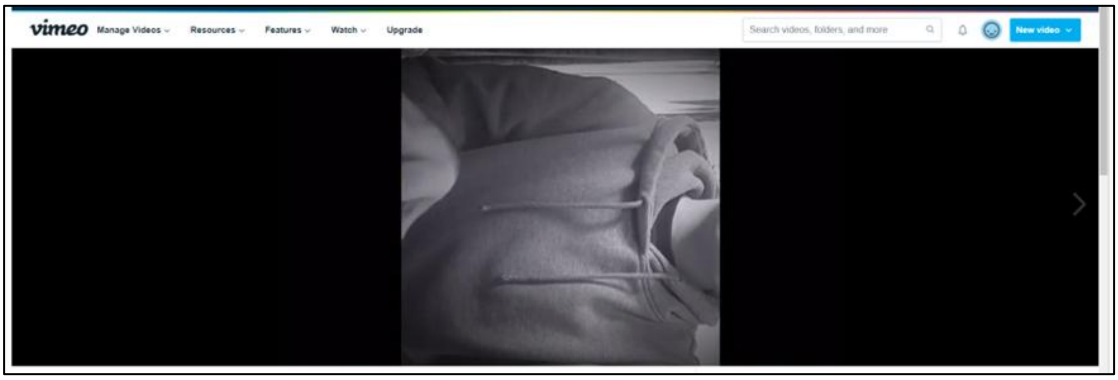


Figure 41 “Untitled 4” by PP7 [Diary image]

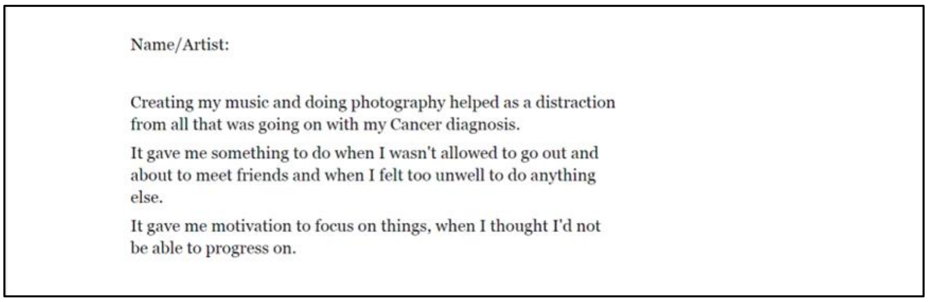
5.21 Labels

Signage has been used by those curating to orientate audiences to exhibitions, as a means of interpretation (George, 2015). Signage as labelling of exhibitions can also use extracts of discussion and storytelling as another creative way to share artists' experiences (Cheu, 2017).

VisualBeats was advertised by those involved as "An exhibition by a group of young adult artists hospitalised with cancer" on introductory A3 signage in two spaces, and on a video screen in the third. The exhibition audiences of other patients, staff, and visitors were invited by the label to "Please post feedback on Facebook, Instagram & Twitter" using the hashtag #** "or contact/message 07***" , my work-related mobile telephone number. It was also mentioned on the label that anonymous comments may later had been included in research.

An accompanying label to PP6's three printed lyrical poems Lucky Stars, Mother and Succeed read, *"VB is really important to me as it keeps my spirits high, it's something to enjoy whilst I'm struggling with treatment and feeling sick xx"*.

PP7's three untitled photographs were exhibited the artist with a label that shared their experience of the project, the ways it helped, and what it gave (Figure 42 below).



Name/Artist:

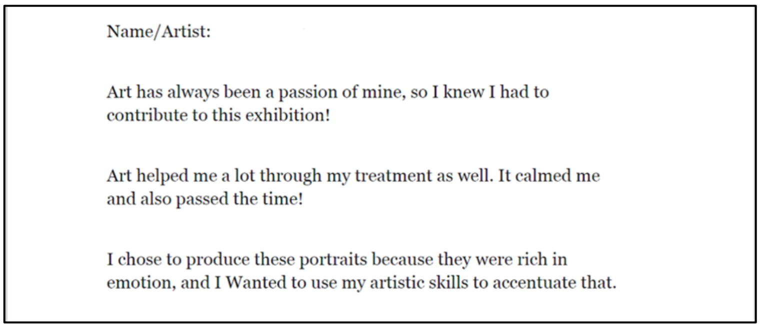
Creating my music and doing photography helped as a distraction from all that was going on with my Cancer diagnosis.

It gave me something to do when I wasn't allowed to go out and about to meet friends and when I felt too unwell to do anything else.

It gave me motivation to focus on things, when I thought I'd not be able to progress on.

Figure 42 Image of label by PP7 (anonymised by Author)

PP2's series of three mounted and black-framed Untitled drawings of faces was accompanied by a label that, similarly, shared their experience of the project as help, alongside some insight into their creative motivation for taking part (Figure 43 below).



Name/Artist:

Art has always been a passion of mine, so I knew I had to contribute to this exhibition!

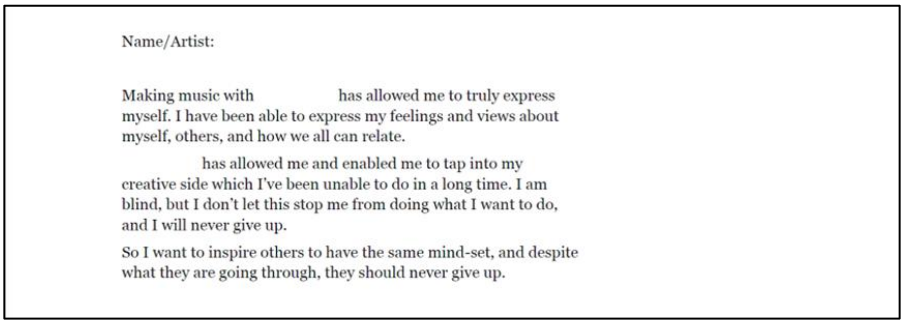
Art helped me a lot through my treatment as well. It calmed me and also passed the time!

I chose to produce these portraits because they were rich in emotion, and I Wanted to use my artistic skills to accentuate that.

Figure 43 Image of label by PP2 (anonymised by Author)

PP1’s Untitled was an audio track in a YouTube video about the exhibition. The label in the exhibition was in the style of a question and read, *“Q. A reason why making music with VB and/or artwork for this exhibition is important to you right now. A. Gave me something to focus on and since I was already interested in music it gave me the perfect opportunity to not only learn a new skill but to also have fun.”*

PP4’s piece We Never Give Up was a large, board with raised-print lyrics, was accompanied by the label that shared their experience of the project as allowing and enabling them to access feelings as well as to creatively express those feelings (Figure 44 below).



Name/Artist:

Making music with has allowed me to truly express myself. I have been able to express my feelings and views about myself, others, and how we all can relate.

has allowed me and enabled me to tap into my creative side which I've been unable to do in a long time. I am blind, but I don't let this stop me from doing what I want to do, and I will never give up.

So I want to inspire others to have the same mind-set, and despite what they are going through, they should never give up.

Figure 44 Image of label by PP4 (anonymised by Author)

PP5’s contribution, the manufactured drone, was alongside a label that read, *“Making music and developing aeronautical projects provides me with an opportunity to focus on a task and get away from any problems or worries that may be on the mind. They both also acts as an extension of thought, or new way to express emotion or talk. When playing the guitar, making music, or designing and producing model aircraft, a lot of time can go by very quickly without me realising because I’m enjoying myself and focusing my full attention to the task.”*

PP3’s - Mugen Splash and Crimson Icon, the graphically designed images printed on foam board, came with a label that identified the artist as, “(alias: Livery Magic)” and the image as *“A 2008 Honda*

Civic that has been illustrated with a raft of Aftermarket modifications, and a monochrome wrap. The wrap/livery is based around the Mugen logo (a popular Honda Aftermarket tuner), and then uses a variety of black and white paint splashes to transform the livery into artwork." Crimson Icon had an accompanying description that read, *"A pair of Air Jordan 1's; illustrated in the 2013 Chicago Colourway. An iconic pair of Sneakers in a bright, simple presentation."*

5.22 Communications

One month into the artworks going on display a video entitled *VisualBeats Exhibition at The Royal Marsden NHS Foundation Trust* had been created for social media by the hospital's communication team. I introduced the video personally (as "a PhD student") and the research (as "the VisualBeats research project") (Figures 45 & 46 below). The contributing PPs had signed an additional consent beforehand for this material to be shared as it was.

Around filmed installation shots and an explanation of its context and content by me, footage from PP5's drone was followed by spoken word by both PP4 and PP6 (from We Never Give Up and Lucky Stars respectively). The video had ended by a typed statement that, "All art, spoken word poetry and music featured was created by the artists involved in VisualBeats at the Royal Marsden," and another statement that the music track that had overlaid the video was created by PP1, as with the film that had featured within the blood test waiting area display.

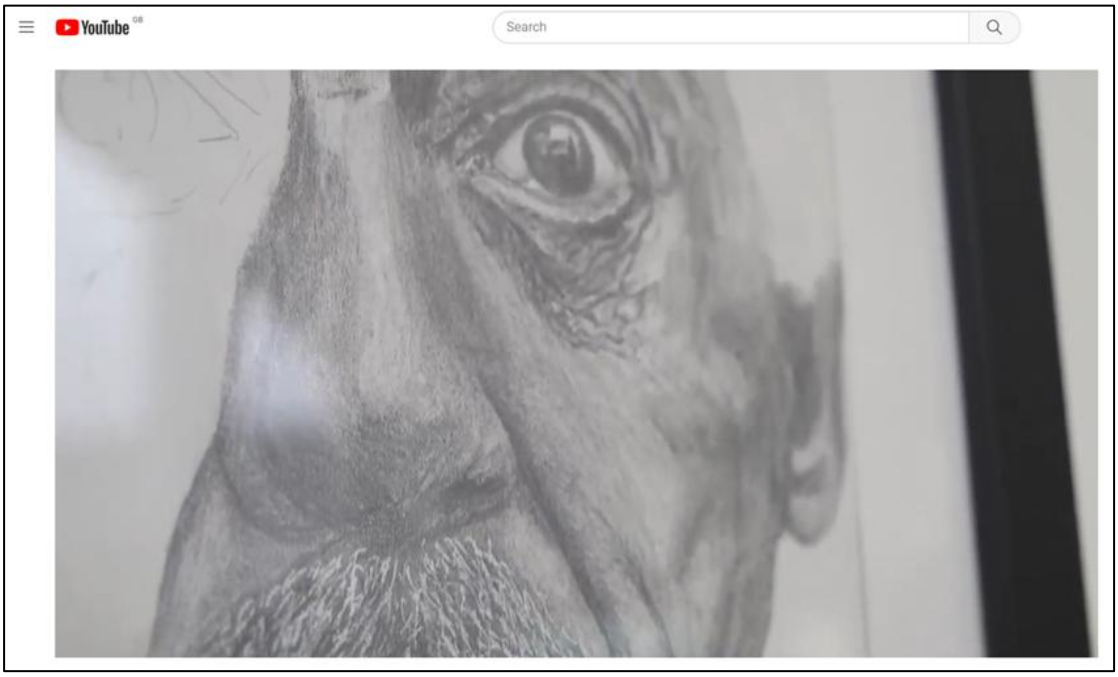
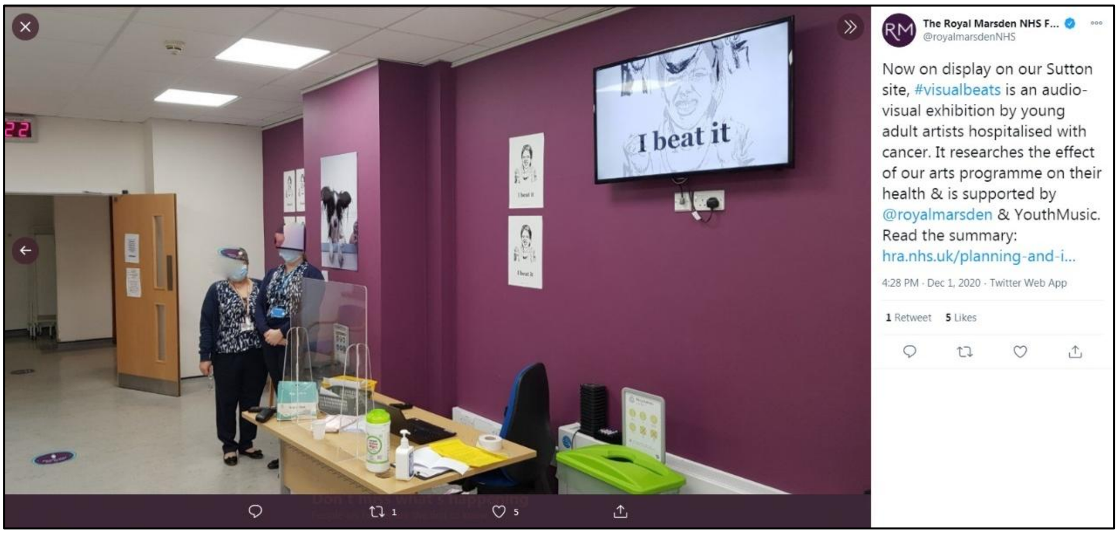


Figure 45 "VisualBeats research project" YouTube video [Diary image]

Figure 46 PP5’s contributions to the “VisualBeats research project” YouTube video stills [Diary images]

Social media posts from the hospital communications team had accompanied the video on social media (Figures 47 & 48 below). Those social media posts included installation images from the displays, which I had provided with consent from the staff members and patients that had agreed to feature.



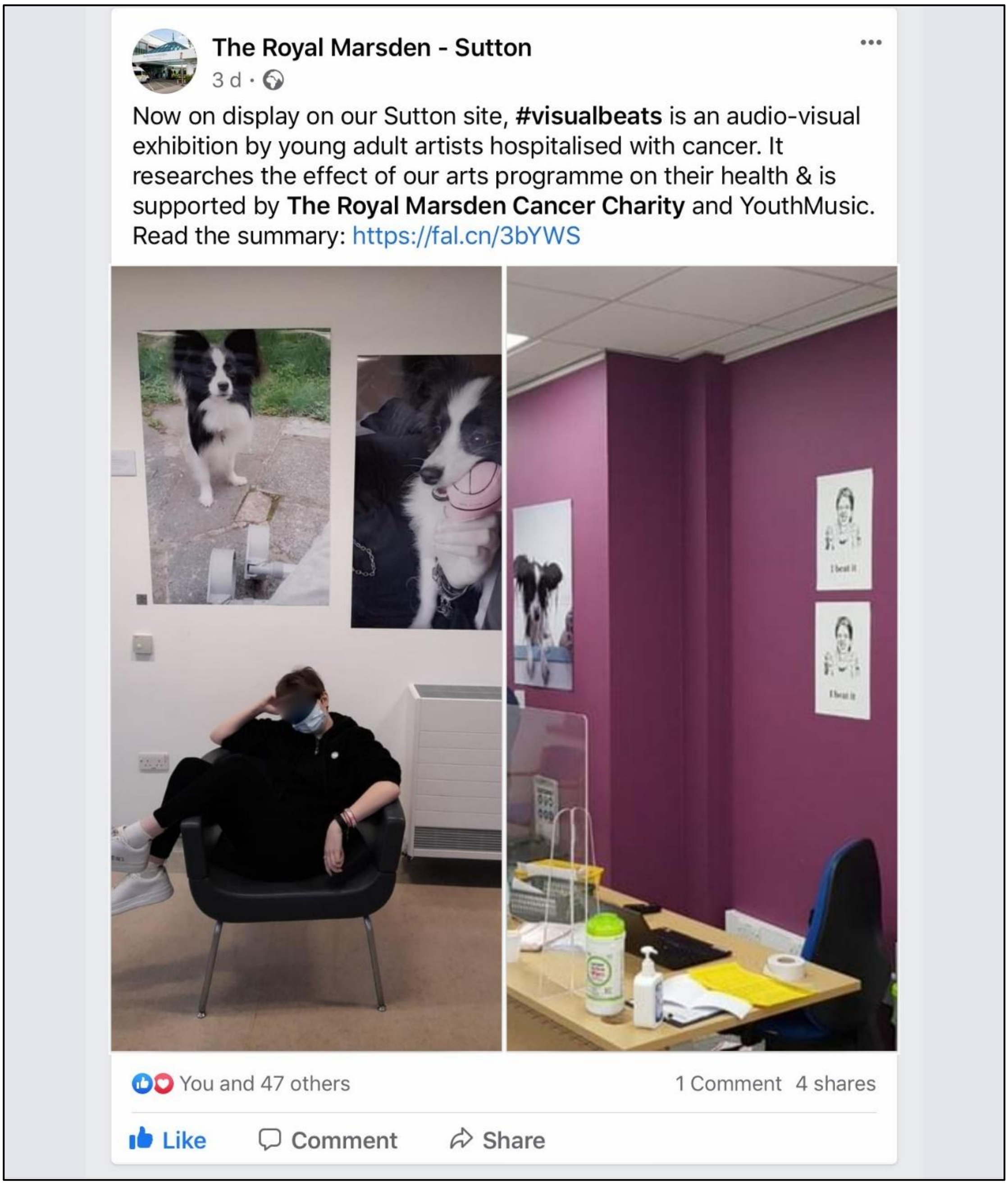
The Royal Marsden NHS F...
@royalmarsdenNHS

Now on display on our Sutton site, #visualbeats is an audio-visual exhibition by young adult artists hospitalised with cancer. It researches the effect of our arts programme on their health & is supported by @royalmarsden & YouthMusic. Read the summary: hra.nhs.uk/planning-and-i...

4:28 PM · Dec 1, 2020 · Twitter Web App

1 Retweet 5 Likes

Figure 47 Hospital social media post (Blood test waiting area) [Diary image]



The Royal Marsden - Sutton

3 d ·

Now on display on our Sutton site, **#visualbeats** is an audio-visual exhibition by young adult artists hospitalised with cancer. It researches the effect of our arts programme on their health & is supported by **The Royal Marsden Cancer Charity** and YouthMusic. Read the summary: https://fal.cn/3bYWS

You and 47 others

1 Comment 4 shares

Figure 48 Hospital social media post (Radiotherapy waiting area and Blood test waiting area) [Diary image]

The social media posts had read "[VisualBeats] researches the effect of our arts programme on [young adult artists hospitalised with cancer] health." This had been adapted slightly from my suggested content, by the hospital communications team.

5.23 Audience responses

Having established the importance of the audience’s role within the tripartite co-curating process, I had then sought to explore their experiences. Again, this data had become available as spoken feedback and emails received, and social media posts viewed during this period.

As the reader may recall from the exploration of workshops positive feedback on the exhibition in general had been posted by a member of the public on Twitter, and the author had shared this with the PPs. In addition to this, feedback had come from staff members that contacted the author directly, during the exhibition, through the organisation’s email system. The staff feedback received included the following direct quotes, as exemplars, which focused on the technical and emotional impact of the artworks (italics for emphasis by the author):

“It is *moving & inspiring* for both staff and other patients to see work done by our patients that *reflects* their *feelings*.”

“This exhibition is both very *varied* and *reflects* the way everyone deals with *emotions* differently.”

“The dog belonged to one of our teenage patients and it was *a great comfort for her* to see him on the wall each day as she was staying away from home.”

“I do find it *uplifting* to see the *variety* of work, from the poetry through to the dog posters.”

“This artwork completed by teenagers is a credit to them. The poems We Never Give Up and Mother are incredibly *moving*, and the expressions used really evoke *feelings* of hope. I especially enjoyed the Mother poem and can fully relate to the *sentiments* - purely from the mother's point of view!!”

“The artwork of the trainers and sports car help to remind us of our youth, they are *striking* pieces and I like the *boldness* of the colours. The pencil drawing of Simon Pegg is particularly eye catching and shows *raw emotion* at its best.”

“The unfinished pencil portrait by [PP2] caught my attention and interest as soon as the exhibition went on display as the face just seemed to be emerging from the paper of its own accord in front of my eyes. This gave it a very dynamic quality and *made me feel really connected to the emotion* of the artwork. It had not had a chance to be overworked or perfected by the artist and this undoubtedly added to the *strength* of the piece.”

“We Never Give Up” by [PP4] was another exhibit which I found very *moving*. In quiet moments I would re-read the poem and it would give me *a sense of calmness*, reminding me “not to sweat the small stuff.” It was full of courage, determination, and strength, making it a *very powerful* piece of poetry.”

There was also feedback received from staff, during the exhibition, about the labelling on display:

“Next time I do think it would have been useful to have had the small plaques with the artist information on a bit bigger for patients to engage with and read, as I think this important information can be overlooked. Unfortunately, in RDAC they were difficult for patients *to fully enjoy* because of the positioning.”

This evidence from the staff encounter will be reflected upon below. I will now transcribe the feedback received on social media, where it featured during the exhibition, which was as follows:

“Sending so much love. Keep going X. Always right by ur side.”

“Wishing you all the strength, power, and positivity. You are strong.”

“Spotted at our local hospital today a collection of art from young adult artists hospitalised by cancer including this great one of @simonpegg. Some simply amazing work”

Finally, I provide a transcription of the single text message feedback that had been received by me, from an anonymous sender that had encountered a display:

“I believe they're all patients. bit of colour. I think anything that catches your eye whilst you are sitting there between chapters is good. any artwork is amazing ad the imagination. the imagination and foresight, to knock it out.”

Before reflecting further on this data, it is important to note that, as per the study design, some audience perceptions of the project were fed back into the workshop conversations as they were captured. A further selection of quotes below were PP’s responding to those that I had fed back:

“In a place like a hospital, it’s probably a place where you have got *to keep that in mind*. Because the people there aren’t necessarily wanting to be there. It is not like they’ve bought a seat there, and they know what they are expecting to get like when you see a show, you know what you’re getting in to. Because it is more of a public place.” (PP1, Workshop 6).

“*I guess **it’s** that art is representing* a part of the hospital. The patients which are there and so on. Just in a small way.” (PP4, Workshop 6).

“I think that’s lovely, to know that what PP4’s written *has touched somebody else* and, like, *make them understand what all of us have gone through. Our own different things*. And the fact that someone else, like, *can understand someone's work and relate to **it***, and relate to any of our works is amazing." (PP6, Workshop 6).

"Really my purpose was *to have that effect on others, and the fact that **it** has that has really touched me*. So, it proves what I was writing *has actually worked* in a sense." (PP4, Workshop 6).

"I guess ***it** served its purpose* of I wanted to inspire someone – at least one person – and influence someone. And the fact *that **it** did* is what *made me most happy*." (PP4, Workshop 7).

I would suggest that, if the "it" being mentioned by the PPs above is co-curating, then the effect it/co-curating had, by promoting new purpose, fostering new relationships, was positive. As the reader will recall from my earlier reviews, most hospital arts projects in the NHS had focused on enhancing a generalised feeling well-being for those taking part (APPG, 2017) and, whilst a widely accepted definition of well-being was elusive, it was suggested that suggested that happiness, personal growth, self-acceptance, autonomy, purpose, relationships, and environmental mastery should be considered (Todd et al, 2017).

In terms of these processes and experiences of co-curating being supportive I was to consider, the reader will recall, those taking part being or indeed not being emotionally and socially engaged (Thomas, 1993, Ungerson, 1983). The transcribed responses above suggested that the audience engaged socially and emotionally in a positive way to VisualBeats.

Examples of how the audience engaged, socially and emotionally, in less positive (or even disruptive) ways were also found. An example of disruption occurred during VisualBeats, that was discussed by me in workshop seven above and will be expanded upon here. In the Blood Test Waiting Area exhibition, the I Beat It the artist had exhibited posters and flyers. On passing through one day soon after installation I'd happened upon a senior nurse who was passing through the space. They fed back that a patient had commented on I Beat It not being appropriate language to use, as *not everyone beats cancer*, and that because of this unit staff had removed the flyers.

At the time, I had thanked the nurse for their honest feedback and had taken the feedback to the next workshop for discussion. That discussion, I'd felt, had to be managed so as not to cause the PPs to feel they had in any way contributed to an unpleasant experience.

Possible audience responses to artworks were discussed by the group. To assist with this, the author drew upon their prior knowledge of how people in hospital, particularly in waiting rooms, may develop their own interpretations and respond to spaces in ways that reflect their internal reality at that time. Indeed, it may not always be possible to produce, or avoid, and overall positive or negative experience for those in the space (Bates, 2019, Wecker, 2019). This is an example of how the *support* had to be considered across the tripartite realm of cancer hospital co-curating.

Reflecting beyond that period of facilitation about how cancer hospital audiences may perceive aesthetic and/or affective disruptions, that museum and gallery audiences may not, was key to consider. As patients, the cancer hospital exhibition audiences have individual perceptions of their disease, I'd found. Research by Leventhal and colleagues (1986) around people with cancer had identified four main components of such illness perceptions— identity, timeline, consequences and cause—to which a fifth component was added called curability or controllability (first suggested by Lau & Hartmann in 1983 with additional distinctions added by Moss-Morris et al in 2002).

Research on these facets of illness perception suggested that people form them in a very active way (Benyamini et al, 2007, Kemp et al, 1999). The components of people's illness perceptions may be strongly interrelated, so that together they form a coherent, logical story of the person's illness (Benyamini et al, 2004) that can resist change even in face of contraindicative medical information (Wold et al, 2005). A diagnosis of cancer, for example, could lead someone to believe in a shorter prognosis compared with similarly symptomatic people not diagnosed with cancer (Orbell et al., 2008). The *care-lessness* experienced by the audience member offended by I Beat It may have been one of very real though negatively contrasting illness perception.

it is the case that even "well" hospital audience members may perceive care-lessness, within an artists' representations of illness, as complex cognitive and emotional factors can drive the formation of well-people's illness perceptions and identities (Rees, Fry, Cull, & Sutton, 2004, Dwidevi & Gardner, 1997. Lalljee et al., 1993). With this in mind, I will discuss my own response to VisualBeats next.

5.24 My response

Initially when encountering the VisualBeats displays my prior experience of sociology had influenced my orientation to the PPs artworks and labels as direct and disarming expressions of their experiences (or using Giddens's 1979 term *critical situations*). My prior nursing career had introduced me to the idea that illness involves a recognition of pain and suffering, even of death, which may only had been seen as distant possibilities by the person before the illness is experienced. VisualBeats, I felt, challenged me to respond to this with some immediacy. It endeared me to "care" in some way.

I had seen first-hand how illness impacts notions of "care" by changing relationships between individuals, families, and "disrupting normal rules of reciprocity and mutual support" (Bury, 1982, p169). For this reason, my perception of the VisualBeats exhibition, as a phenomenon seen anew, was profoundly philosophical.

My engagement with the artworks together had been on an aesthetic level during installation. I reflected within the diary that the hang felt to de slightly disruptive, almost graffiti-like, but it wasn't until I witnessed the displays completed that the significance of this became clearer. I knew that historically; graffiti has been part of a social movement aimed at reclaiming control of public spaces through community art, asking (urban) society to "care". I recalled that the protest-centred nature of graffiti (Wechsler, 1974) had led people within the breast cancer awareness movement to use the artform to reclaim a "voice" (International Visual Sociology Association, 2016). As a whole, the VisualBeats displays did feel like they were indeed a collective voice saying something. I just wasn't sure what that something was, in these initial stages of responding.

After viewing the displays, and considering my initial response to them, my engagement with VisualBeats became more metaphorical. I was aware that Susan Sontag's 1978 book *Illness as Metaphor* had framed people's understanding of the relationship between disease metaphors and illness experiences (Clow, 2001, p293). Regarding the role of the visual artworks themselves, Susan Sontag had stated that artworks' distinct features are that they do not give rise to conceptual knowledge but to something like an excitation, a phenomenon of commitment (2001). I realised that it was such excitations that had perplexed me when experiencing VisualBeats.

In keeping with my sort and sift approach, exploring my perplexment further, at that time, involved considering Heidegger's concepts of being in the world, temporality, and a care as a phenomenological structure (Heidegger, 1927/2011). Central to this was *Dasein* as an individual's enquiry into being and as people's ability to question and focus on their existence (Takkal et al, 2018, Heidegger, 1927/2011). The literal English translation of Dasein as *there being* and implies that we exist both as an individual and within a social context (Pascal, 2010). I therefore chose to use *there* *being* (sometimes interchangeably) as an English translation of Dasein for reflecting on my response, Dasein being a more accessible concept that also echoed perhaps more contemporary concepts of being “present” and “mindful.”

From this newly reached conceptual vantage point VisualBeats was explored by me in more depth, and in relation to being in the world, temporality, and what I had re-considered to be a “care-full” structure that included an element of there being on the part of those taking part in VisualBeats (Heidegger, 1927/2011, p28). Adding this phenomenological lens had enabled me this more nuanced, viewpoint as a health researcher (Friesen et al, 2012), which I will explain further.

Heidegger (1962) had proposed that fundamentally, *there being* was about caring, as a *concernful* involvement in the world. The world, according to Heidegger’s phenomenology, was made up of our concerns interplaying with temporal elements including the past, present, and the future (Wilson, 2014). Heidegger’s key to experiencing *there being* (or Dasein’s) existence was through a *clearing* in which these elements were acknowledged, some say (after Dreyfus, 1991). A common metaphor I had discovered for expressing a phenomenological clearing was being in a forest, where we’d experienced a moment of seeing the beauty of a tree for the first time, rather than a series of trunks and branches (Smythe, 2005).

Three artworks had been discussed in detail by Heidegger in his lecture *Origin of the Work of Art*. When discussing what had been titled Shoes by Vincent van Gogh (1853 - 1890), painted in 1886, Heidegger mentioned that the artist’s interest in painting them was for their poetic power. Van Gogh had made still lives of this subject that were was not so much the shoes, as what the shoes had represented.

Heidegger’s “Origin of the Work of Art” took readers through the different steps of the phenomenological experience with the Van Gogh painting of the shoes. I immediately made parallels between the phenomenological significance of that artwork and my experience to another in the VisualBeats exhibition by PP3 (See Figure 49 below). For me, Crimson Icon demonstrated Heidegger’s main point about an artwork’s ability to reveal that it may not just be an object of aesthetic appreciation, but a claim to truth, which in PP3’s case may be that they cared about being in the present with its current fashions, and cared about becoming a designer who may create their own (Haug, 2020). What is more, that they selected to display this interplay of past, present, and future to a hospital audience (including me).

Figure 49 Vincent Van Gogh’s “Shoes” [Van Gogh Museum, Amsterdam (Vincent van Gogh Foundation)] & PP3’s “Crimson Icon”

The label beside PP3’s Crimson Icon artwork read, *“Graphic Design has given me a purpose in 2020. I have studied many fields and professions during my 22 years, but I've never mastered one before. Now is my chance. Since February 2020, I practiced day in, day out, to become the best designer I could be finding my style and learning critical skills. Then the chance came to exhibit what I had learned via VisualBeats. To collaborate with other designers and musicians in a similar position to myself. Me, my work, and my passion had found a home. Here. And I can't thank them enough for the opportunity.”* For me, PP3 had provided *a poetic unconcealment* of their *there being* (after Glendinning, 2014).

In terms of the Heideggerian structure of caring, understood ontologically as caring for self (Selbstsorge), caring for others (Fursorge), and caring for interventions or things (Besorge) (Inwood, 2000), I came to consider the wider VisualBeats exhibition as offering a temporal clearing for PPs to care for and about their *there being*. I was aware from my previous nursing research that living with and beyond cancer brought with it issues of temporality. Living with cancer is fundamentally an existential state of *there being* that can call into question the possibilities of both being and non-being.

From a Heideggerian perspective, the existential concern (or angst) of the uncertainty with which a cancer diagnosis and treatment is experienced can understood as caring about the significance of one’s mortality There was a Heideggerian concept of Fear, presenting itself as dread and terror which for those on cancer treatment “is always present, like a ghost that surrounds them” (Alvarez & Sales, 2020, p6). Was it this that I felt through the artworks?

I did not feel that to be the case for VisualBeats. For me, the artworks represented a truth happening, a clearing (Ross, 2006), and a *critical* unconcealment (Glendinning, 2014). But what, I wondered, was VisualBeats not concealing for me? I considered if my slightly anxiety-provoking perception extended to thoughts about mortality, about death itself.

Heidegger’s account of anxiety was aligned with his account of being-towards-death. Anxiety, for Heidegger, was about there being and its basic state. My considerations of the PPs experiences, as artworks, was that they had spoken about how the group experienced their past, present, and future. For me, they had voiced what was “existentially possible” (Dreyfus 1991 p190). I realised that I had not yet considered other more interpersonal ways of interpreting the artworks, such as by considering biographical disruption (Williams, 2000, Hubbard et al, 2010), or loss of social “self” for the PPS involved (Charmaz, 1983). Indeed, I would need to look for other clues to understand the PPs lived experiences. I brought that more socially oriented approach to understanding the PPs experience of cancer hospital co-curating to the theming stage of my research, which will be discussed in the next chapter.

5.25 Summarising the transcriptions and reflections

In this chapter I have explored the processes and experiences of cancer hospital exhibition co-curating through generating transcriptions from and around the workshops, and of the exhibition labels and communications. I have also told the story, in this thesis, of my own response to the VisualBeats exhibition as finally displayed. It is this consideration of VisualBeats as a wider cultural exchange, I feel, that develops my exploration beyond those in the earlier reviews that merely suggested the potential value of co-curating for enabling patients to supportably experience new creative social agency within an institutional setting.

Elsewhere, I'd found (and discussed above) that exhibitions had been considered transformative sites of cultural exchange, through being critical (Hansen et al, 2019). The displays of VisualBeats, I felt, and the reader may agree, indeed functioned both as a display of individual elements but also as well as a critical network of those elements (Tan, 2020). The artworks, despite being displayed using varied mediums and techniques succeeded in a critical way (Gaitan, 2013), by offering a symbolic rupture for the audience, as a whole (Bishop, 2012).

Paul O'Neill's The Culture of Curating and the Curating of Culture(s) (2012) talks about successful exhibitions as being "cultural bridges". The "dramaturgy" of the VisualBeats display, and the "discourse frame" (after Filipovic, 2013) provided by the display's paratextual features such as labels, helped create this cultural phenomenon.

Precedents can be found where artworks similarly displayed together have created new meanings for an audience (after DeNora & Ansdell, 2014). Themed exhibition encounters take place primarily through the artworks displayed, however, paratextual features can have unexpected ideological, political, didactic, psychological, social, and pedagogical effects (Danbolt, 2019). In the case of VisualBeats, however, I needed to go a step further to consider how these effects, as qualities of hospital co-curating's processes and experiences, may be "care-full" or indeed "care-less".

Whilst this will be considered thematically in the next chapter, here I will mention the notion of "exposition" that Schwab (2019) introduced into as an area of artmaking practice. I mention this as my concern here, in summarising and reflecting after the transcriptions from VisualBeats, that my exhibition may have exposed the PPs in some care-less way.

I recalled the discussions at Curating the Medical Humanities, a conference at Birkbeck (University of London) in 2018 that had focused on the ethics of exhibition-making, consent, and the technicalities of curating the work of those with health conditions. That conference had questioned whether "curators" should insist those taking part in the health exhibitions rename anonymous, or to not do so Ultimately, Curating the Medical Humanities acknowledged the ways exhibitions might, through informing about lived experiences of health, have been considered as empowering. Nevertheless, it was discussed by those assembled (including the author) at Curating the Medical Humanities how such exhibitions could become “spectatorial” if attention is not paid to the authentic voice of any patient participants in the exhibition narrative, and how patient participants may be vulnerable to challenging audience responses. The following findings chapter, involving theming of the VisualBeats PPs experiences, will explore these concerns around “care-fullness” and “care-lessness” further.

In terms of audience responses, including my own, the success of the co-curating endeavour has here been measured in its successful provision of aesthetic and affective conditions that have created some social disruption (Lambert, 2018, O'Neill et al, 2016, Back & Puwar, 2012b).The cultural impact of the VisualBeats exhibition, for the audience, came from relationships and dramaturgy created between the artworks displayed (after Filipovic, 2013 & Gaitan, 2013). As a network of elements (after Tan, 2020) VisualBeats prompted a range of experiences that, for some (including the author) whilst not always pleasurable, were curatorially successful in the oft transformative thinking they had fostered (after Chong Cuy, 2013 & Hansen et al, 2019).

6. Findings/Generation of the themes

For this thesis chapter, I explored the VisualBeats workshop and exhibition stories told above, as thematic considerations of co-curating as caring. This was carried out as part of the second thesis objective to focus my explorations on a way that meaning could be negotiated, codified, and presented (Williams & Moser, 2019).

The loosely defined concept for thematic exploration, the reader will recall, was that of caring as promoting autonomy in the context of supported living. Indeed, this was just one way of thinking about caring which, I had come to realise, once being looked for could almost be seen anywhere (Tronto, 2015).

Ultimately, I felt that this definition indicated accepting that the personalised stories I was telling, *matter* (Brechin et al, 1998b). I was looking beyond caring as physically tending to someone (Parker, 1981) and was suggesting being somehow emotionally and socially engaged with them (Thomas, 1993, Ungerson, 1983).

Within health contexts, I was aware that caring as *mattering* could be demonstrated within acts on behalf of others that involve both physical and emotional labour (Conradson, 2003), and intentionally placing people’s dignity and respect at the *centre* of any physical and/or emotional care endeavour (CQC, 2022). I was aware too that, in the UK, best practice for *cancer care* had stated that, where appropriate, people diagnosed with cancer should have access to more *personalised* care (Macmillan Cancer Support, 2022) that included personalised *support* (Henry et al, 2014). The basis for providing this specialised form of a caring relationship was because cancer treatment had historically been neither physically nor emotionally gentle (Clow, 2001). Person-centredness, I’d found, was a concept that had been developed through programmes such as those at the UK’s King’s Fund (2013) and NHS Institute for Innovation and Improvement Patient Experience (2013).

A notable change to how care provision had become objectified in health contexts was with the shift from a welfare to a market paradigm of health service delivery (Groys, 2022). As part of the associated market culture, people (as patients) had become recast as customers seeking care (Brechin et al, 1998b).

In my prior hospital nursing practice, I recalled, caring nurse-patient relationships had also entailed an acknowledgment and negotiation of power (NMC, 2024). Such negotiations, when carried out positively, had been considered health supporting for patients as customers of care (Held, 2007, Sevenhuijsen, 1998, Tronto, 1993) with independence promoted over dependence within the nurse-patient relationship (Fraser & Gordon, 2002, Groenhout, 2004).

“Good” supportive nursing had meant not only attending physically, mentally, and emotionally to the needs of the customer, and committing to their needs and personal growth during the caring relationship (Mitchell & Agnelli, 2015, Hayes, 2014, Davies, 1998), but also inviting them to make personal choices and express personal opinions (Hope & Saville, 2023, McKie, 2005, Renzetti et al, 2001, Kittay, 1999, Kosberg & Garcia, 1995, Qureshi & Walker, 1989). “Poor” or perhaps care-less nursing meant disempowering, disabling, inducing dependency-inducing and being *unavailable* (after Hope et al, 2022).

Acknowledging my own understanding with regards caring as a concept had been important when generating my themes. I‘d created a visualisation (after Brechin et al, 1998b p10), to assist with this, which is shown in Figure 50 below.

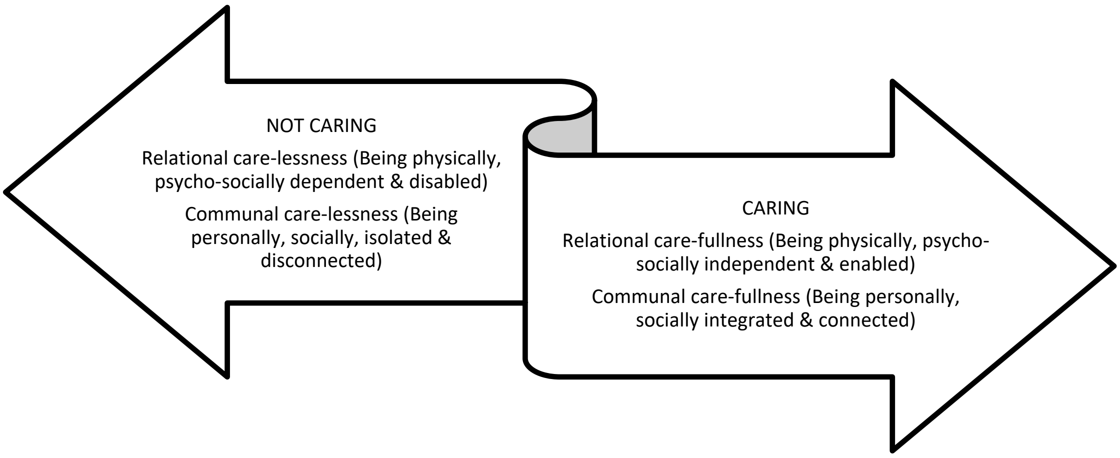


Figure 50 Visualisation of caring/not caring (for theme generation).

The generated themes below had been considered by me as an active autoethnographic “agent” (Trainor & Bundon, 2021 p3). I had been looking of examples of *good or poor caring* involving shared reciprocity and decision-making, and respectfulness for the other’s personal choices and opinions. I particularly considered, when negotiating, codifying, and presenting the data, *in what ways* the project was successful in terms of promoting autonomy in the context of supporting living.

The process I’d chosen for developing and generating the themes was to firstly consider the patient participant experiences as workshop discussions, and secondly consider my own experiences as diary entries. This two-step process, it was hoped, would commit me to considering the PP’s stories over my own when developing my thematic.

The structure I’d chosen for presentation of the themes generated was to do so in an exemplificative way, declaring the essential nature of the theme and then presenting exemplars. My rationale for presenting the themes in this way was to suggest to the reader the nature of each theme as reflecting the essential human experiences (van Manen, 1990a) from within the personalised stories.

6.1 Participating (theme one)

Firstly, then, I had considered the hospital exhibition co-curating workshop PP discussions thematically and in relation to caring as a relational activity that promoted autonomy in the context of supported living. Following the theming process set out earlier in this thesis, two candidate themes were developed in relation to considering the PPs individual and shared experiences of the exhibition project as caring. These candidate themes acknowledged that in terms of creative collaboration, publicness and exhibiting, the project had *promoted autonomy as a group of collaborative creators, rather than as patients* and *supported connections with each other and with a hospital audience*, for the PP's.

Apart from the obvious pitfalls of attempting to speak on others' behalf, at this stage I had been concerned that analysis had been reached too soon, which can often be the case (after Braun & Clarke, 2022). As with other trainee researchers before, semantic categories may have mistakenly been considered as themes, and those patterns erroneously reported on by me (Thorne, 2020). I had also felt that this initial approach to coding had also perhaps lacked *nuance*, as again can be the case (after Braun & Clarke, 2012). This lack of nuance may have been because the initial stages of data analysis sought semantic rather than latent content within the PP's transcripts. I realised I had erroneously looked for too much meaning in the surface level of the data.

Returning to the literature around thematic analysis had provided me with guidance around locating core meanings within PP quotes that had appeared in more than one candidate theme. This focused more on developing more conceptual interpretations, which was a next necessary step in the analytic process (after Wiggins, 2017). Table 2 below summarises the process of revising themes of PP workshop discussion, presented to give the reader insight into the final themes generated.

Table 2 Revisions made to my PP workshop discussion themes

Candidate theme initial descriptor	**Reflections on refining/defining/naming**	***Revised themes (and descriptors)***
The project as a way for us to connect with each other and with a hospital audience	These quotes described more personal sensorial (“touch,” “hear,” “seen”) and emotional (“interpret,” “relate” “inspire” “freedom”) experiences, rather than two-way connections.	***(All) feeling humanly connected.*** *Curating as a way of experiencing positive sensorial and emotional engagements (with the audience)?*
The project promoted our autonomy as a group of collaborative creators, rather than as patients	These quotes were by far the largest group, and as such in some ways felt like a catch all option. In many ways, described the experiences of making art, rather than making the exhibition.	***Becoming creatives (not patients).*** *Curating providing the opportunity to be an artist/ make art (for this and other projects)*
The project as a way for us to learn new things	These quotes focused on the patients’ developing new talents. It seems important to acknowledge, on read through, that these were transformative experiences of developing artists, creating artworks.	***(Creating and) learning, developing, transforming.*** *Curating generating experiences of developing and sharing creations for the first time, in new ways*

Next, the datasets had been revisited accordingly and then clustered into eleven further refined codes. Appendix C contains details from the rounds of coding in tabular form, with exemplars and key reflections in- and on- coding (after Maietta et al 2021, Braun & Clarke, 2012/2021). The final three themes of *(All) feeling humanly connected*, *Becoming creatives (not patients)* and *(Creating and) learning, developing, transforming* were selected as best describing and organising the PP’s experiences of the exhibition project, as interpreted by me, and in relation to the research question.

When reflecting around *(All) Feeling Humanly Connected* as a theme from the PP's workshop account, I had considered whether this experience had been impacted by the COVID-19 pandemic. The pandemic had enabled original approaches to the exhibition planning workshops, by opening a digital space in which the PP's could connect. The power of social media to encourage new relations was, I recalled, evidenced elsewhere during the pandemic (Hall et al, 2021, Marzi, 2020). Whilst the facilitatory challenges faced by me may have been seen initially as impeding, the digital space may have provided a means to equalise the relationship between PPs, and even between the me (as researcher) and the PP group.

I had also considered that arts interventions had been found to foster connectedness through a *human desire to create together* (after Sharpe, 2010). This linking of creativity to improved social well-being or sociality may have been another experience for the PPs (after Wright & Pascoe, 2015). Bone and others (2022) had, importantly I felt during the analysis, found associations between arts engagement and increases in social and psychological health for young adults.

Thematically considering the VisualBeats workshop data had suggested the group aspects of co-curating could have contributed to PP's feelings of self-confidence and sense of belonging on what has been termed a *human* level (after Zarobe & Bungay, 2017, Bungay & Vella-Burrows, 2013, Daykin et al, 2008). The human aspect of this theme was also generated from my understanding, again introduced above, of improved health (or indeed illness) experiences being linked with human societal behaviours (after Green & Thorogood, 2004). It is suggested that co-curating, as the human (and therefore health) behaviour investigated here, may have addressed the PPs lack of visibility and voice (as agency) within the relational structure of the hospital (after Albano, 2018, Smith, 2020, O'Neill, 2012).

When reflecting around *Becoming Creatives (Not Patients) as a theme* from the PP's workshop account, I had considered discussions around PPs' identities as *artwork-makers*. I'd felt, on reflection, that the artwork-making may have been considered a more important feature of the curating, than the co-curating itself. There was an established link evidenced elsewhere between the experience of artmaking and patients feeling less nervous, anxious, and stressed (Holt, 2020), but something more was felt to be the case when considering the VisualBeats project.

It had been acknowledged by others for some time that artwork-making may occupy a liminal space in which normal social roles and hierarchies are suspended, and those involved are temporarily freed of everyday conventions and constraints (Turner, 1974). It was significant, I felt during the analysis, that the patients were ambivalent about the title of artist that was used by the author in the Patient Information Sheet, and on social media. I acknowledged Matarasso (2019) had stated that, in participatory art, the boundary between amateur and professional artist may less rigid than people assume. The descriptor of "artist" was employed by me to inspire those taking part to make confident statements about their curatorial "exposition" on the exhibition labels.

Elsewhere, artwork-making had been shown to provide a therapeutic outlet; a solution for providing support for people when they are ill (Sonke et al, 2015). Artwork-making can indeed afford patients an opportunity to retain familiar personal and social identities, and to resist being *dominated by illness labels* (after Reynolds & Prior, 2006). The VisualBeats workshop transcript data suggested, I felt having analysed the data thematically, that the artwork-making undertaken as part of the VisualBeats PP group appeared to have been a meaningful activity that may have had a positive impact on the PPs sense of personal and shared creative identity (after Ennis et al, 2018).

When reflecting around *(Creating And) Learning, Developing, Transforming* as a theme from the PP's workshop account, I had lastly considered what any transformation may have been taking place. As the reader may recall, exhibition displays can be considered as unique sites of cultural exchange through being critical and transformative (Hansen et al, 2019). Also, that creatively engaging with the arts can transform young adult's views of themselves and their futures (Mannay, 2021), and provide individual psychological support (Fancourt et al, 2023), increased feelings of purpose in life, and improved personal growth (Packer & Ballantyne, 2011, Papinczak et al, 2015).

In the case of VisualBeats, I suggest, any transformation the exhibitions offered had gone beyond that of the individual co-curator to a wider social/organisational level. *How to Biennale! The Manual* (Patel et al, 2018) had recognised the even greater importance of co-curating for making connections outside of formal institutional structures and expectation, and I felt that seemed to be happening here thematically.

Disrupting these structures and expectations through exhibiting, had transformed the PPs social standing (as perhaps increased social capital) and that this may be more transformative still when co-curating within hospital spaces, where social capital may be scarce for young adults (Stromgren et al, 2016, Pejtersen et al, 2010, Suzuki et al, 2010). Social capital has been seen by some as an important determinant of health (Ahnquist et al, 2012, Giordano et al, 2012, Murayama et al, 2012), I had also noted then.

In terms of caring as a relational activity that had promoted autonomy in the context of supported living, I lastly used the thematic process to revisit the concepts I had come across so far in the development of the thesis. As discussed above, autonomy (as agency) could have been considered alongside personal growth as an ill-ness related experience of well-ness or indeed wellbeing (Todd et al, 2017). Also, that cancer treatment can negatively impact on young adults' sense of autonomy could have been tackled by PPs through improved peer relations (Sodergren et al, 2017). Bringing these novel conceptual and thematic elements together, as thematic analysis, I then generated, as an overarching first theme, that *cancer hospital co-curatorial participation be considered a creative, connective, and transformative activity that promoted autonomy.*

6.2 Facilitating (theme two)

Secondly, I had considered my own hospital exhibition co-curating facilitation thematically and in relation to caring as a relational activity that promoted autonomy in the context of supported living.

Again, following the theming process set out earlier in this thesis, it was first found that of the 654 sections of workshop discussion attributed to facilitator contributions, just over half (346) had demonstrated active listening and language that mediated thinking for the patients. An example of how the facilitator applied a caring yet challenging, motivational language style was by asking *"How could we start to move towards you reaching that solution? So, what do you think is a realistic way – or an unrealistic way – of moving towards that?"* An example of how the facilitator applied paraphrasing and checked understanding was by asking *"The last comment I wanted to check with you was what people have said before about them being kind of inspirational, but also like motivational for you. And I guess motivational means, you know, all sorts of things to different people. Am I right that's your feeling? That it has been quite an inspirational, motivational kind of experience working with them?".*

Table 3 (below) provides a fuller vignette of my facilitation style (or "artistry"), as adapted to the co-curating workshop context. A tabular representation of reflections around all conversation styles analysed are available in Appendix B.

Table 3 Vignettes of my facilitation style

Event/Source	**Artistry**
Workshop 4 *Transcript* *November 11th, 2020*	*Researcher "I tell you what J, I mean, one of my questions tonight for you guys was going to be when and if you, any of you are going to be coming into the hospital – I know at the moment it's pretty tricky with the restrictions – but sometimes you have appointments and you're coming in. And I do not know if and when you are next due in J, but I could always, you know, whenever you want to come and see it, of course you can see it. I will get you in. But if you…I have. the two pieces they delivered in addition, they are still wrapped. If you wanted to collect them and* ***have a look in person****, so you would not have to come into the hospital, or I can post them out to you. It is up to you – something like that."*

	(Patient) "I might be coming in December. Possibly coming in December but I will have to double check my calendar, if not then you could post them over. That would be great, but there is no hurry because I know posting during December is probably going to be a bit of a nightmare because of all the Christmas stuff. So yeah – either or – but you know if posting it is the best option then there is no hurry whatsoever. *Researcher "I mean, do you want me to just take a good photo head-on of the piece on the wall* ***so that you can actually get a good look at it and see what you want to do****?"* *(Patient) "Yeah sure, that would be great."* *Researcher "Yeah, shall we start with that then* ***we can*** *take it from there?"* *(Patient) "Yeah sure"* *Researcher "And if you want me to get it cropped down at the bottom, then I can, then that is no problem at all. No problem – I mean,* ***this is your exhibition so if you want to add stuff and take stuff out you can entirely do that****. And, you know, if you wanted to send some digital images of designs you have done since, for me to add to the digital exhibition, you know on the screen, then* ***we can*** *do that too. So have a think about that, yeah? If we have got two sets of printed,* ***we can*** *have some different images on the digital display, if you want."* *(Patient) "That I can definitely do."*

That I'd *adapted to motivate* was proposed as a first theme from my/the facilitator's workshop account. Next, I'd turned to their reflective diary to consider internal observations of facilitation, and to reflect on these thematically in relation to promoting autonomy in the context of supported living. This motivation to generate findings from the reflective research diary was also driven by my understanding that, additionally, "reflexivity encourages us to strive not to be complacent and to continue to review and critique our own research practice" (Cassell & Symon, 2004, p. 506).

My facilitation diary, as also described above, had taken the form of a word-processed document, made up of research project field notes and images (including a drawing), alongside a series of emails sent securely to an institutional email address over the course of VisualBeats. Although the drawing was a spontaneous activity, it had been included as it was found that drawings had been a viable ethnographic fieldnote method previously (see Bonanno, 2023). Diary content for the co-curating project workshop had, the reader will recall, invited reflection on any tensions, mistakes, revelations, decisions, compromises. Sections were also available where notes on personal practice and further reading were able to be recorded.

Again, each day spent managing the research I had made a reflective diary entry. Entries were usually an email sent to my secure organisational email account titled “thoughts.” Thoughts and observations focused both on practical issues as well as how the research has been experienced as a social encounter (either face to face or mediated). Typically, observations included comments on how well (or not) the project, and/or the relationships it depended on, were progressing.

This diary content had also, it was found during analysis, included several “questions to self,” which are often found elsewhere in the diaries of early career researchers (Engin, 2011). Such questions to self can represent *intramental* thinking (after Mercer, 2001) that considered possibilities, rather than just reported or shared procedural information, and revealed itself during my reflexive thematic analysis as “a window into the process of constructing knowledge” (Engin, 2011 p300). My questions to self were, it was found, thematically direct and blunt, but showing a willingness to be vulnerable which can be key to a successful autoethnographically inspired exploration (as per Ellis, 1999).

As with the analysis of the workshops for theme one, for theme two I’d reviewed each diary code cluster as critical/practical, and each quote was assigned to a developing candidate theme to ensure a pattern of meaning-unity and conceptual coherence (after Braun & Clarke, 2021). Once again, I had understood that the frequency of quotes being assigned was not necessarily an indicator of the significance of a theme.

Three candidate themes were then developed in relation to considering the experience of facilitating VisualBeats: *inviting new voices into hospital spaces*, *practicing flexibly*, and *being person (or patient-)-centred*. These candidate themes, I’d felt, led to more questions than answers at the early stage. As well as representing patterns of facilitatory behaviours, there seemed to be a set of underlying principles or virtues of being a “care-full” (or “care-less”) facilitator.

Returning to the literature for guidance in relation to analysing the data further, I had found Engster (2005) proposed three “virtues” of caring as, “qualities necessary for best meeting the aims of caring" (p54). These three virtues included attentiveness (loosely defined as empathy and the ability to anticipate needs that another person might have), responsiveness (loosely defined as engaging in dialogue with others about their needs), and what I would subsequently term *respectfulness* (loosely defined as treating others in ways that do not degrade them in their own eyes or the eyes of others and by acknowledging the abilities they have (also after Tronto, 1993).

Having found examples of my endeavouring to be attentive, responsive, and respectful within the diary, and bringing the thematic elements above together, I generated as an overarching second theme, that *cancer hospital co-curatorial facilitation be considered a reflective and adaptive activity that supported living (with cancer).*

6.1 Summarising my themes

Having attempted to answer what the processes and experiences of cancer hospital exhibition co-curating as caring had been, using a more reflexive thematic analysis, I had next sought to interrogate the dual themes generated towards thinking critically about the “practical philosophy” of my curating (Newman, 1999). It was hoped that this “expositioning” process of co-curating could enable an improved application of my own and others’ practice.

The dual themes generated from the analyses were that cancer hospital exhibition co-curatorial participation is a creative, connective, and transformative activity that can promote autonomy., and that co- curatorial facilitation is a reflective and adaptive activity that can support people living with cancer.

In summary, and together, the dual themes had offered significant new technical knowledge about co-curating as a complex, collective, consensual, and *caring* health intervention. This claim is made through analysis of language used by the co-curating group during the intervention, and by me during facilitation, which suggested that it was experienced in certain supported and supportive ways. Reflexive thematic analysis that drew on Braun and Clarke’s recommendations, and reflective diary keeping based on Schön’s recommendations around being a reflective healthcare professional, also enabled this robust interpretation of those experiences as being dynamic and communal.

In Figure 51 (below) I had visually summarised this cancer hospital co-curating thematic as an interconnected “communality”. Within this communality, opportunities for the co-curating to be more “care-full” presented themselves not just through techniques associated the creations, connections, and transformations of patient participation, or the reflections and adaptations of facilitation, but also suggested a more active role for the cancer hospital audience.

I chose to label this interconnectivity as a communality because concepts of caring can increasingly be found in non-hospital communal (or community) arts settings, where projects are increasingly concerned with caring for the well-being of the participants, the artists, and the audiences, instead of, say, caring about economising (Millner, Coombs, 2021, Tan 2020). Feeling cared about, in these community arts projects, has been said to be generated by all people involved being brought together (Conradson, 2011), encouraging new senses of identity, and of self-worth (Basting, 2017, Milligan &Wiles, 2010).

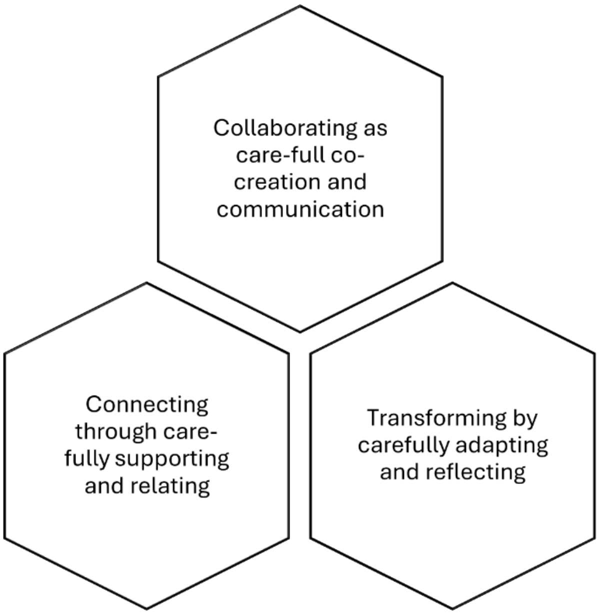


Figure 51 Cancer hospital co-curating as an interconnected communality.

It did not seem unreasonable, I hope the reader would agree, to have drawn parallels between VisualBeats' and these wider community arts phenomena. Indeed, returning to Martin Heidegger's concept of caring in relation to art's way of *being in the world*, and *caring* as expressed through caring for the self ("Selbstsorge"), caring for others ("Fursorge"), and caring for things ("Besorge"), (Heidegger, 1927/2011) suggested successful cancer hospital co-curating to be a process of care-full communality and supportive experience on wider philosophical level. For this to have happened successfully, I suggest, required a series of interconnected care-full techniques which will be discussed next.

7. Discussion, contribution, and conclusion

In this final chapter of the thesis, I assess and discuss what my doctoral research has explored and achieved in terms of new knowledge. Key to assessing that exploration, as the reader will see, had been my success in highlighting aspects of an area of healthcare *that might otherwise have gone unnoticed* (after Eisner, 1991).

I suggest that my adapted autoethnography went beyond *mere authorial expression* (after Duncan, 2004) and demonstrated original scholarly thought about cancer hospital co-curating as caring. Of course, I will discuss any limitations of my research, proposing how these may be remedied by further exploration. Having suggested and discussed these points I will then offer the reader a conclusion to my thesis.

7.1 Discussing my findings

In this section, I discuss the research as a successful exploration of the processes and experiences of cancer hospital exhibition co-curating as caring. As the reader will recall, before beginning the research I had observed anecdotally that my hospital curating activities may have encouraged artistic expression, creative development, and the social cohesion of those taking part. Being stimulated to better understand curating activities as crossing boundaries of both arts and health practices, and because the lack of hospital-focused exploration, I had sought to explore further. I had then reviewed the evidence base in relation to the focused field of study and, finding that little existed, formulated a research question to address this.

I'd then designed what I felt to be the most optimal methodological steps to conduct my research, adapting autoethnography as my approach to recording my journey as a trainee researcher. The co-designed embedded VisualBeats protocol was developed, and the study took place. The findings generated from the study were then presented first as descriptions, analyses, and visualisations, and then as reflexive and thematic considerations.

Consideration had first involved telling the stories of a facilitated co-curating project with a group of patients receiving treatment and a hospital audience. A second step was taken to reflect around and consider any themes of caring associated with the stories from the cancer hospital co-curating project. Having generated dual themes from the considerations, I then suggested a series of interconnected care-full techniques were involved in what I had, before the research, the anecdotally observed artistic expression, creative development, and social cohesion as qualities of cancer hospital co-curating practice.

Here I will discuss the interconnected communalities of cancer hospital co-curating as caring that I found, further. Table 4 (below) sets out how I see the techniques involved in *being* as taking part in the phenomenon being demonstrated. These techniques, I suggest, could be considered as *know how* and *know that* knowledges, though considered with caution as the technicians may not (yet) be aware of their technical participation.

Table 4 Techniques of cancer hospital co-curating as caring

	Collaborating as care-full co-creation and communication	**Connecting through care-fully supporting and relating**	**Transforming by carefully adapting and reflecting**
Patient participants	Being/feeling confident to join a face to face or online group and contribute to display-making	Being/feeling able to take part in discussing shared experiences of display-making and to consider the experiences of others	Being/feeling invited to voice novel ideas and to develop new perceptions through paratextual features
Facilitator	Being/feeling competent to manage the collaborative display-making by the group	Being/feeling skilled in discussing the experience of, and the experiences of others to, in the workshops	Being/feeling able to promote the development of novel ideas as paratextual features
Audience	Being/feeling available to encounter the exhibition through carefully placed displays	Being/feeling receptive to what is communicated through exhibition labels and other media	Being/feeling responsive to developing novel perceptions from the ideas presented

I appreciate that this may be a bold suggestion, and one based on the generated findings from one small-scale qualitative research study. Scholars had been opposed to the development of widely accepted standards for qualitative research and have suggested that universal criteria would be at best problematic, and at worst fruitless (Guba & Lincoln, 2005). Tracy's eight-point key markers for assessing such criteria, however, are helpful to discuss here. Included in those points were that the project has a worthy topic, rigor, sincerity, credibility, resonance, a significant contribution, ethics, and meaningful coherence (2010). Ultimately, I must leave the readership to decide if they feel the topic of study was worthwhile and sincere. I hope their feeling is that it was. How rigorous, credible, ethical, and coherent the research is the job of this thesis' examiners, though will be touched upon below.

The meaningfulness of the research, I feel, deserves some extra attention here. I was reminded on completing this thesis that "care is founded on recognition", and that we must provide authentic contact that takes in account the social isolation of the ill (Vickers & Bolton, 2024 p119). This research, I suggest, was meaningful in its authenticity towards recognising the experiences of those that encountered it.

For example, the research will likely resonate with those who were ill, or those who were in contact with those who were ill, during the COVID-19 pandemic. During the years of this study, I was also involved in reviewing the literature around the psychological and emotional impact of the COVID-19 pandemic on people living with cancer. My colleagues and I had concluded that anxiety, isolation, and uncertainty about the future were particularly acute for people living with cancer during this time (Muls et al, 2022).

We had noted that the studies reviewed had used tools that did not provide deeper understanding of how and why emotional states of people with cancer were affected. This research had been important in qualitatively exploring the impact of COVID-19 the experience of people affected by cancer, through authentic contact. Such analytic generalisations should not be mistaken, I propose, for simplicities. My approaching the research by seeking subjective knowledge, I suggest, elucidated "complex truths" (Creswell, 2015, Crotty, 1998).

The UK Medical Research Council (MRC) had defined complexity as having interacting components. The thesis' describing, analysing, and considering of complex effects of cancer hospital co-curating, and attempting to further comprehend these as an interconnected communality, may represented a significant step towards considering co-curating as a complex health intervention. A caveat to this claim may be that most interventions in hospitals are complex as hospitals are complex systems (Shepperd et al, 2009). Nevertheless, because of my exploration, hospital co-curating can now be rethought as complex intervention, with its dependency on some techniques of those facilitating and taking part in the intervention (Craig et al, 2008), for it "provide better healthcare" (Benyamini, 2011 p306).

I was also to discover, during the course of this research, that these techniques of hospital co-curating, as a complex intervention, could also be considered their *active ingredients* (after Warran et al, 2022, also see Appendix H). As qualitative research, this thesis provides an in-depth exploration of how people interact through engagement with cancer hospital co-curating, and what facilitation is involved. Telling the stories of these perspectives in this thesis has increased the value of qualitative paradigm for informing arts in health practice (Swindells, 2017, Barnett-Page & Thomas, 2009), and the health-related value of hospital co-curating as an activity.

Returning to the rigor and ethicality of this thesis's explorations, I suggest that, by incorporating artful elements of both sociology and EBCD, a more robust model for hospital based curatorial practice had been explored. Indeed, as research is a role intimately connected with that of being a curator (French, 2020) that all hospital co-curating projects could (and should) be exploratory in some way is suggested. The development of the VisualBeats protocol through a multi-level ethical approval process was a first step to offering such a blueprint for developing future, rigorous hospital co-curating research.

Also, in terms of credibility, I hope that, by exploring the authentic stories in this thesis, a divide between the lived experience of illness and academic analysis of those experiences may have been bridged (Frank 2000). The research, and this thesis, may also offer new credibility to the role of the hospital curator, who could now perhaps claim to have a role in understanding and people's experiences of healthcare, and improve those experiences, through their practice (after Johnstone, 1999). Co-publishing peer-reviewed papers about the techniques found in the communalities and how those translate into improved experiences, as is planned, can only increase the transparency and credibility of this adapted autoethnographic research (Anderson, 2006).

7.2 Contributing

In this section, I consider the original contribution of this thesis to the wider practice and field. That a working hospital arts programme manager has produced this thesis signifies, again, the meaningfulness of the endeavour as just such a contribution. A principal contribution may be in its "proto professionalisation" of HAPMs alongside other regulated roles such as nursing and arts therapists.

Hilton and Slotnick suggested proto professionalism had been an emergent state in which an individual healthcare worker developed the technical knowledge needed, to acquire a level of "professionalism". Referring specifically to medicine, they had said that sophisticated reflexivity on the junior medic's part had been required to produce insights enabling the individual to "professionalise" (2005). Proto-professionalism had also been referred to as an *art* informed by experiential judgement (related to Schön's knowledge-in-action), following a period of learning, instruction, and reflection. I am hopeful that this thesis coherently conveyed the *art* of hospital art co-curating for the case of one HAPM.

In terms of what the research may have contributed beyond the NHS, the National Organization for Arts in Health in the US had been seeking to "professionalise" hospital arts management roles through the establishment of an Arts in Health Professional Certificate. That pursuit included developing a Core Curriculum for Arts in Health Professionals alongside reviewing and revising a Code of Ethics and Standards for Arts in Health Professionals (NOAH, 2023/2018). It was hoped my exploration, and the new technical knowledge gained, may contribute in some way to that international work.

Of course, as with any qualitative exploration, this research can only contribute this new technical knowledge as an analytic generalisation, rather than as a particularised probability (after Gibbert et al, 2008, and Barlow et al, 2008). Also, and as mentioned earlier in this thesis, I appreciate that adapting a subjective/autoethnographic approach may provide another limitation (Nurani, 2008). Works in which the auto ethnographer is more memorable than the autoethnography, and more absorbing than others involved, had been criticised (Atkinson, 2006). I hope that, by richly featuring others accounts in this research, I may have avoided this impression here.

Another obvious limitation has been around the small amount of people that took part in the exploration. It is possible that a large section of the hospital community's experiences of the research will have been missed precisely because many may have had little or negative interest in taking part in facilitating, making or encountering the hospital exhibitions. Another limitation was that of recruiting a convenience sample of PPs for VisualBeats from within the wider arts programme. Whilst still information rich, this could have represented a threat to data validity for readers. An alternative view could be to have regarded the PP group as an intensity sample, being made up of those already engaged with the arts programme in a consistently heightened way. Despite these real concerns, I am encouraged that the overall value of small-scale qualitative approaches within wider health research continues to be defended (Lyons, 2011, Greenhalgh, 2016).

In terms of a limitation of the study design perhaps becoming an opportunity, one aspect stands out. As the reader will recall, an adjustment made in response to the COVID-19 pandemic was to move to mobile rather than face-to-face communications with the PPs. This included using a closed messaging application's video calling feature (WhatsApp) using a hospital mobile phone, to conduct the Workshops. Having requested this option, the PPs also used the feature to share messages and videos with me, and with and each other. This could be, and should perhaps be, considered an additional (and unintended) space and/or place in which the co-curating had taken place., However, consenting to, and using, this content as data for the purposes of research was not included in the ethics amendments agreed by the university.

Within the literature, projects conducting messaging application focus groups proposed that enhanced engagement may be enabled through a virtual space that is more familiar to participants (Marzi, 2020, Fox et al, 2007). The instant messaging functionality may have given participants, as key informants, more time to reflect on their responses (Abrams & Gaiser, 2016, Skelton et al, 2018). Unfortunately, those responses could not have been included in detail, although they were alluded to within the diary.

For the VisualBeats protocol, instant messaging on WhatsApp not only enabled synchronous and asynchronous discussion to take place, but the platform and the smartphones used to take part in the workshops (as opposed to laptops) allowed the extra step of sharing video and other content. The workshops unexpectedly became participatory video sessions in which, as others during the pandemic (Marzi, 2021), promoted technical s development, capacity-building for those taking part. It has more recently been proposed that adjustments to the COVID-19 pandemic may have encouraged such shifts towards a more "commons" approach to curating from which "new constellations" of agency could emerge, have taken place (Richter, 2022 p42).

7.3 Concluding the thesis

During the writing of this thesis Simon Sheikh proposed curating has become, “a vehicle for researching into something specific…experimenting with various forms of public address and congregation, building, or even antagonizing communities, whether designated and located or universal and unknown, inoperative or becoming” (2019 p99). I end this thesis with the suggestion that the exploration has invited the reader to regard my exploration of cancer hospital co-curating as a first attempt at driving or at least handling such a vehicle carefully.

The problem identified at the outset of the thesis had been the lack of knowledge around co-curating as a creative health intervention in hospitals. The thesis sought to better define any lack of knowledge, and to better understand the theories and practices of co-curating as a creative health intervention in one NHS cancer hospital, as a unique setting with challenges that are unique to it. With research on arts, health and wellbeing crossing many academic disciplines in a fragmented and diffuse way (Stickley & Clift, 2017), this thesis also sought to better understand itself (and the co-curating process) theoretically and practically around a concept found at the centre of both arts and health – care.

This thesis ends by better understanding cancer hospital co-curating as a care-fully focused practice and one proto-professional feature of hospital arts programme management (HAPM) as a standalone, proto-professional practice. The thesis has shown how HAPMs can, creatively and collaboratively, and working in a reflective and adaptive way across boundaries and disciplines allied to health, optimally impact on health experiences.

Locally, the thesis has explored an area of health service delivery that helps the NHS towards meeting challenges of the future (Dougall et al, 2018) including working with communities defined as having specific and often unmet needs (Fortier, 2023). The VisualBeats communality the co-curating generated was something that would otherwise not have taken place (Mabaso, 2016). It may have mattered locally but that does not mean it should also more widely, according to recent government policy on creative health which acknowledges the contribution smaller scale studies can make to the field (GLA, 2024). This mattering, or caring even, can hopefully be achieved through peer-reviewed publication of the thesis’ findings, in cross-disciplinary academic journals, as a further “reflective conversation with the situation” (Schön, 1983, p268), increasing ownership of the situation (Byrne et al, 2018), and encouraging more to explore this unique aspect of the HAPM’s repertoire.

Appendix A Tabular representation of initial literature review

Search Terms Used and Results

Search number	**Database/Source**	**Search terms**	**Initial results**	**Notes**
1 curator/ing/ial as a concept in the literature	HDAS (AMED, BNI, CINAHL, EMBASE, EMCARE, HMIC, Medline, PsycINFO, PUBMED)	curat* curato* curator* in combination of Title only	curat* 31902 curato* 278 curator* 240	curat* included many references to “curative,” data/database/digital curating, Data Practices and Curation Vocabulary (DPCVocab), curatopes melanoma, “curator” as a concept in Nordic society composed of 3 roles: careers officer, social worker, and teacher, Curator as a historical role in medical societies
2	HDAS (AMED, BNI, CINAHL, EMBASE, EMCARE, HMIC, Medline, PsycINFO, PUBMED)	exhibition* in combination of Title only and Title + Abstract	exhibition* 7925	Exhibition is a phrase used in pathology, exhibitionism in mental health contexts, reviews of exhibitions with medical themes in museum or gallery spaces, and later still “Exhibition of Specimens/Patients/Cases” and “Instruments” as “transactions” in medical societies, trade or industry exhibition studies, and art therapy (some used by me due to unavailability of anything else), also “currere” education-based method.
3	DelphiS	Curator OR curatorial AND hospital in Title	1957-2019, academic journals, 10	1 relevant (Moss & O’Neill)

4	DelphiS	Exhibition AND hospital	1957-2019, academic journals, 122	Older more obscure material
5	JSTOR	Cancer in Title and Exhibition in All Fields	1957 to 2020 37	Dominated by breast cancer/feminist literature
6	Google Scholar	Used full Protocol terms but simplified/de-anglicised “Patient curating as a complementary way of researching the experience of music making for young adults in hospital with cancer”	2010 to 2020 (last ten years as includes citations) 1700	“Research” produced many irrelevant results
7	Google Scholar	Used full ERGO terms “Using curatorial methods to explore and exhibit the experience of a live arts programme for young adults hospitalised with cancer”	684	

Articles selected and reviewed

Author, Year and Aim	**Eligibility – Is it a study/thesis talking about curating/exhibition making as research practice/intervention?**	**Methods –Design and data collection**	**Participation – Number, setting, diagnostic criteria, and demographics**	**Finding(s) – Reported, timescale, measurement**	**NOTES**
Moss 2019 Explores “the role of the curator in hospitals”	YES	Qualitative, phenomenological study. Semi-structured interviews.	Ten hospital arts specialists in UK, Ireland, USA, Canada, and Australia	Five themes (1) Patient involvement and influence on the arts programme in	“The role of the hospital curator is a ground-breaking specialist role that can bring benefits to hospital life”

				hospital (2) Understanding the role of the curator in hospital (3) Influences on arts programming in hospital (4) Types of arts programmes (5) Limitations to effective curation in hospital. Recommendations made.	
Bryce 2014 Explores “how a community arts exhibition produced by a group of mental health service users can be a form of knowledge production”	YES	Notes on collaboration and feedback from the interactive exhibits were collated and thematically analysed by a subgroup of CAST	A group of mental health service users, staff and governors who are interested in promoting the use of Arts throughout the Sheffield Health and Social Care NHS Trust	(Unclear) Emerging?	Further analysis required?
Sarginson 2005 “To provide a project of creative activity involving the entire local hospice community that would raise spirits and generate a better understanding of art practice in palliative care.”	NOT EXPLICITLY	“a non-validated, enquiring, reflective approach”	Preparation of exhibits was centred in the day hospice. The exhibition ran for 5 days, was available to at least 350 people which included patients, visitors, volunteers, staff, paramedics, drivers, and 61 people attending a memorial service. Forty-four visitors attended specifically to see the exhibition.	1. A diary of activities kept by the project leader 2. Qualitative-assessment questionnaires for staff, patients and visitors authorized by the clinical services manager. These began in the first week of preparation and ended with a staff email questionnaire 2 months after the exhibition	Demonstrated that a memorial art may be a fundamental adjunct to the care of dying patients' families and the bereaved

				3. Anecdotes recorded in writing by the project leader. These were mainly collected from patients during the arts sessions 4. Two-month follow-up questionnaire. This was limited to 20 staff in addition to anecdotal quotes from 2-day hospice patients.	
Bartlett 2019 Explores how "concepts from object relations psychoanalysis can help to rethink the point of entanglement between curating and health as a process of preparing the ground for audiences to do generative psychological work with images and affects."	YES	Around a co-produced exhibition ("Group Therapy"). Data from a visual matrix responding to the first iteration of Group Therapy made up of 12 participants with an interest in health practices, drawn from arts and cultural organisations across the Northwest of England.	Through a series of workshops, artists invited service users, mental health professionals and other stakeholders to answer the question: if you could design your own asylum, what would it be like? Exhibition then designed.	The key theories from object relations psychoanalysis (ORP) in this paper are containment, Reverie and transitional phenomena. Aim is to show how exhibitions can support psychological processing of challenging stimuli by discussing how one audience group responds to the Group Therapy exhibition.	Largely about the visual matrix as a method.

Appendix B Tabular representation of reflections on facilitation conversation style

Transcript example	**Responsive facilitation style and curating/creative purpose**
“I know we had a conversation before this about your interests which are not necessarily musical but, in terms of creativity. Over to you, tell us about your experience.”	*Open ended question* *Inviting discussion about individual creativity*
“I suppose the magic question is – is they could do anything with you, what would it be?”	*Magic question* *Encouraging wildly creative thought*
“It is entirely up to you what steps you want to take. Whether you want to have a think about it or have a chat between yourselves – what are your thoughts?”	*Motivational question* *Encouraging creative thinking*
“How could we start to move towards you reaching that solution? So, what do you think is a realistic way – or an unrealistic way – of moving towards that?”	*Motivational question* *Encouraging action/progress(ion)*
“And is that something that you would see yourself writing up? Or would you need the help of someone else for that to be produced? How would you best like that to look?”	*Motivational question* *Say what you need*
"I totally take your point about wanting a theme. I think that, um, that is something that K had mentioned, that it felt a bit vague.”	*Paraphrasing (others)* *Saying together*
“We are going to do like a raised lettering print so, because you wanted to make it more tactile for people, is that right?	*Motivational question*

	Affirmative
"I wanted to check with you that – you know – my thoughts on what you were saying were correct. So, a couple of key words kind of stood out. One was around the fact that VB seemed to be helping you improve a skill. A skill that you have got. And I am seeing you nodding, but would you all agree that is one of the features of the programme?"	*Paraphrasing* *Consensus checking*
"The last comment I wanted to check with you was what people have said before about them being kind of inspirational, but also like motivational for you. And I guess motivational means, you know, all sorts of things to different people. Um, and it, am I right that's your feeling that it has been quite an inspirational, motivational kind of experience working with them?"	*Paraphrasing* *Checking understanding*
"I mean do you feel that is a reasonable assumption to make? Or do you think there's other areas I should be looking at to get feedback?"	*Exploring possibilities* *Encouraging thoughts*
"So, what do you think about that bit of feedback, and also do you think about my reaction to it?	*Exploring possibilities* *Checking practice*
"What do you guys make of both those things – the space that I'm proposing and the show that I'm getting inspired from?"	*Consensus-checking*

Appendix C Tabular representations of code and candidate theme developments

Participating – Coding

Code (with number of occasions noted) in alphabetical order	**Description/definition (guidance regarding its application)**	**Origin (when first featured)**	**Importance (rationale for why it matters to the study)**	**Example (verbatim quotation)**	**Counterexample (a text segment that might be confused as part of this pattern, but which is not given the definition)**	**Reflexive coding (how the code evolved as familiarisation progressed)**	**Inductive coding (how the code evolved whilst considering creative collaborations, publicness and exhibiting as research (Puwar & Sharma, 2012)**
Audience feedback (30)	Talking about perceptions of audience, based on information received	At the “Assessing Success” workshop stage or discussion	Audience feedback generated much discussion	*“And the fact that someone else, like, can understand someone’s work and relate to it, and relate to any of our works is amazing.”*	*“I agree and it is just to get that acknowledgment of, like, just the talent that is being exhibited. And some of us that have not been doing this very long”* (relates to peer support and encouragement)	Pattern evolved due to the strength of responses to feedback from staff emails, social media posts to patients’ work. This was later in the transcripts.	We discussed audience (staff, patient, and visitor) written and spoken comments in the workshops, which gave rise to patient responses about “effect,” “provoke” “reactions,” “interpretation” “opinion” “response” and “acknowledgment.” This code developed out of latency of this content. I decided not to call this

							code “public feedback” as the hospital audience is not a public per se.
Co-doing (22)	Taking about experience of working with others in the workshops or project more widely	PIS “Asking you to take part in the exhibition planning process in this way is known as “co-designing” and being “co-curatorial”.”	Collaboration (as “co-designing/co-curating”) was a key feature of the project and discussed at all stages. It should be noted that these discussion points were often introduced by the researcher	*“So maybe just a bit more integration with everyone. Like, it can still be individual work but just more of a closer kind of, er more involvement with other people sort of thing I guess.”*	*“I just know what would be accompanying the music that would help. But other than that, if me and Zani can do like a session a week, that would be perfect.”* (Relates to collaborating with a musician outside the workshops)	This pattern evolved as a “catch all” for any patient discussion that was responding to the researcher’s encouragement to work as a collaborative group.	These naturally changed across time from being polite and cautious to more knowledgeable about peer creative strengths. Although initially this had been coded as “collaboration” I felt on reflection this represented my interpretation. It did not reflect the confusion that the comments suggested around “co- “. What are the experiences around “doing”? Words used were “create,” “come up with” “put together” “achieve” “doing” and “done”
Creative skills NOW (19)	Talking about patients’ own (or others’) creative ability	Whilst not explicitly addressed in the PIS, artistic ability was often raised by potential	Artistic ability was not a defined concept within the project. Ability and skills to	*“In all honesty, I am a little bit nervous that what I create is actually going to be good enough for this*	*“If it’s ok, I was going to send them over to you. Um I have no idea on editing or anything like that.”*	This manifested in discussions around confidence to take part	Pattern of discussion about trepidation that began at consent stage. Although I had coded this

		patients during the consent process (usually patients perceived themselves as lacking ability, rather than being overly able to take part).	create was assumed through taking part.	*exhibition. If I am really honest, because I am good but I'm not outstanding.”*	(Relates to no having any experience at all)	and patients perceived personal creative skills	as “artistic ability” it occurred to me that I was applying a longer-term label/latent concept to what was actually a discussion around ability at that time, in relation to the exhibition and its timeline. Words used included “good enough,” “skill level,” “my scope.”
I can (36)	Talking about (planning/agreeing) what the exhibition can potentially contain	“Starting Off” This will involve chatting about what putting on an audio-visual exhibition might look like and sharing examples of other exhibitions.	The idea of planning and agreeing content as a group was a key feature of the project and discussed from the outset	*“I could have it at the end of the track if PP4's cool with that. So as the track finishes you then hear A's vocal message.”*	*“I just told you what I did. And the – and yeah, we got something together in the short time we had. But yeah, I mean I don't think there was any real restriction anywhere, shall I say.”* (Relates to ambiguity of content)	Pattern from discussion related to thoughts and feelings about the “theme” of the exhibition, and how this affects artwork/content	This code was initially called “exhibition content” but on reflection, the experience of the patients would appear to have been about the sharing of ideas, rather than reality of the end product made. Words used included “I can, I could,” “try and create,” “I thought,” “I need,” and “sounds like a good idea”
We could/you could (55)	Talking about how the exhibition might be installed	PIS “The purpose of these discussion groups will be to plan (or “curate”) the exhibition”.	“Curating” as an abstract concept a key feature of the project and discussed from the outset	*“What if you create like, um graphics that we can hang like beside the screen? And so there will be like K's video on screen,*	*“That I can definitely do. Definitely – because everything is formatted in RGB for screens anyway.”*	Pattern of discussion around responses to goal-oriented questioning by the researcher, about how	These codes started as exhibition design then it became clearer the patients were talking about potential

		"Asking you to take part in the exhibition planning process in this way is known as "co-designing" and being "co-curatorial".		*with music, and then next to that if you have graphics sort of um in the same style as K's artwork?"*	(Relates to personal technical skill)	the exhibition will look as a whole	collaborations where they feel others' skills may be needed for the exhibition itself, and for promoting and sharing it once open. Words used included, "you could," "you can," "I could" and "we can."
It (the exhibition) (53)	Talking about the exhibition more broadly/in expanded terms (real and imagined)	"Being Inspired and Having Ideas" This will involve an opening discussion around ideas for the exhibition.	The one-off exhibition as a whole/larger concept was a key feature of the project and discussed from the outset	*"Despite what we have gone through and so on, we still have talents, and we are still able to show what we can do. Um, yeah, and express us – it is a form of expression."*	*"The work I'm doing now, that woman that I'm drawing, that's on paper so that would need framing."* (Relates to display of personal work, outside of current exhibition discussion)	Pattern of discussion about thoughts and feelings expressed about the exhibition concept as a whole	Although I started coding this as "the exhibition concept" it became clear that this was my own semantic interpretation of latent content. Words used by patients were "It" (a lot) to describe the exhibition, "representation" and "interpretation."
Encouragements (22)	Talking about peer creative possibilities supportively	"Turning Ideas into Reality" This will involve turning real ideas into something we can exhibit and sorting out who is doing what.	A non-directive approach that left space for discussion around patients' creative ideas was sought	"I am just really impressed, um, by how talented everyone is, in their own different way. Um, either at being art or writing or music or whatever it is. It is nice to	*"I like the idea. Like the whole kind of idea of what is going on. The exhibition, and what not. I think it is really cool"* (relates more to the exhibition concept, rather than an idea)	Pattern of positive comments between patients about each other's' abilities and contributions	This code started as peer support; however, I realised that I was again applying a concept from prior learning to what was, in fact, early polite encouragement. Words

				see that” (relates to general supportive acts)			used included “Wow,” “good,” “nice” and “cool” in response to peer’s sharing of ideas, artwork, and music early in the workshops.
(Im)practicalities including COVID-19 (75)	Talking about negotiating challenges to putting on the hospital exhibition (including during a pandemic)	“Planning and Evaluating” This will involve thinking about practicalities like space planning, safety of the exhibition, and how we will get feedback.” “Putting the Show Together” This will involve exploring the practicalities of putting up, invigilating, and taking down our exhibition.”	A space to discuss any challenges faced was sought.	*“I would, but my only issue is getting it to the (hospital). Because obviously it is about a 2-hour drive and because it is so big it won’t fit in any of our cars.”*	*“Um yeah that is the part that just yeah just getting interactive and seeing each other and er like in my case I did not get to record. Again, that was all down to covid.”* (Relates to impracticalities around covid restrictions specifically)	Pattern evolved out of discussion around real challenges faced being hospital patients, and the additional layer of caution and risk assessment procedures that were imposed in response to the covid pandemic.	Code evolved as reflected upon, from general challenges faced to more specific limitations caused by factors such as COVID-19 (which limited contact and hospital visits) to disease (loss of sight) and location (wide referral area meant that patients lived remote from the hospital/exhibition site). Words used included multiple times “problem,” “quality,” “circumstance,” “issue” and difficulties and (im)possibilities of the COVID-19 “rules”
Patienthood (20)	Talking about the experience of being a patient, not necessarily related to the exhibition	PIS “We know that cancer and its treatment can affect a person’s physical and mental health.”	That patients were a defined group within the research was a key feature of the project and discussed from the outset	*“I have had chemotherapy this year which has not been successful, and I have just recently gone through radiotherapy. Erm, as a*	*“I haven’t spoken to him yet. I know Zani mentioned that, because of treatment, his hands are a bit shaky. Uh huh So yeah,*	Initially began being recorded as “Prior inter-patient relations” and “Treatment” but merged together into Patienthood	Again, on reflection this code may represent an “othering” of the patients. Words and phrases used did not include “cancer,”

				result unfortunately I have lost my sight completely. Erm but I am trying to not let that stop me from doing what I want to do."	*he hasn't really been playing guitar."* (Relates to passed on information about health status)	for way of a better descriptor	in fact the word cancer did not occur within the first workshop at all.
Prior doing and dabbling (98)	Talking personally about creative practice	PIS "You will not have to provide any footage or recordings of your own music-making to take part in the exhibition, and you will not have to perform music to take part in the workshops. There are many things you could do to help put the exhibition together, such as agreeing written information that is published for the exhibition or discussing technical points about how the material could be exhibited."	Individual creativity and the encouragement of all to contribute to the exhibition as artists was a key feature of the project, and discussed from the outset	*"I am definitely a visual artist, a graphic artist, graphic designer. I have really got into it I would say, this year. I had dabbled in it maybe 2019, 2018, sort of dabbled with graphic design but 2020 I've sort of dove all in."*	*"I will probably go for like a similar type of vibe, similar type of beat but I will be able to use more instruments to make it more emotio*nal. I guess." (Relates to suggestions that complement another's ideas, but non-specifically)	Pattern evolved from the early discussions group members took part in related to their individual artistic practice, before they joined this research project	This code was initially named prior personal creative practice, but again this reflected the researcher's approach as a fine artist. It did not reflect the practices described, which were most my described in terms of "doing" (part, present) and "working on" or "my work" but also "playing" (though this can describe engagement with an instrument as well as informal practices) and "dabbling"
VB (64)	Talking about prior participation in the wider music-making programme	PIS "In this study we would like you to participate in organising	That the initial theme of the exhibition would be the wider VB music making programme was a	*"It was good because they were up for, like, anything – anything musical. It didn't have to be*	*I could work alongside VB and Q to try and get the right music for it."* (Relates	Pattern of discussion around the ever-present "theme" of the on-going music programme	This code was used to capture feedback about the wider programme. This feedback will be

		an exhibition related to the VB music programme."	key feature of the project and discussed from the outset	*beatboxing, or on the computer. It could be real instruments. It was whatever you wanted to do. They would do it with you and make it fun which was really good."*	to future plans with the VB musicians)		expanded upon in more detail in the facilitator's experience of exhibiting as research using model of reflection session

Participating – Developing a theme

Clusters	**Candidate themes**
Cluster 1- exhibiting	Audience feedback, It (the exhibition)
Cluster 2 – creating	Co-doing, Creative skills NOW, I can, We could/you could, Prior doing and dabbling
Cluster 3 – collaborating	Encouragement, Patienthood
Not clustered	(Im)practicalities including COVID-19, VB

Facilitating – Coding

Code in alphabetical order	**Description/definition** **(guidance regarding its application)**	**Origin (when first featured)**	**Importance (rationale for why it matters to the study)**	**Example**	**Reflexive coding (how the code evolved as familiarisation progressed) drawing upon Schön**
Boundaries	Talking about/capturing	Mid way through workshops	Was in relation to gathering material for display, hesitation around pressuring those taking part	*"I did notice he had a clinic appointment he did not seem to be aware of. Tried to think if I should pursue that with him?"*	Pattern evolved due
Covid	Talking about/capturing	From the outset	Was in relation to the increased tightening of COVID-19 restrictions	*"Wrote to infection control with plans to use Gordini Room. PC wrote back saying that is fine!"*	Pattern evolved due
Developing solutions	Talking about/capturing	At the making stage	Was in relation to negotiating creative ways forward with the artists and others	*"Spoke to new PP for 45 mins. Did not want materials in voice or large text, did not mention braille. Said can't touch things in hospital so relies on descriptions."*	Pattern evolved due
Spaces (empty versus curated)	Talking about/capturing	From the outset	Was in relation to the importance of starting with a "blank" space in which to exhibit (white cube?)	*"Reclaim space/repurpose collection/decolonise? Also replacing means they are good enough?"*	Pattern evolved due
Involvement & inclusivity (role)	Talking about/capturing	At the latter workshop stage	Was in relation to making sure everyone taking part felt involved	*"Really encouraged this morning to see messages from PP2 and also*	Pattern evolved due

			and able to make/contribute to the exhibition	*from musicians. Started messaging PP1 then deleted – decided to call him instead”*	
Self-questioning	Talking about/capturing	From the outset	Was in relation to feeling unconfident, unprepared	*“Didn’t hear responses properly – emotional touch points missed?”*	Pattern evolved due
Support (for me)	Talking about/capturing	During exhibition phase	Was in relation to developing relationships with other key people (YSC, print room, comms)	*“YSC emailed to say PP has been asked what he wants to do in relation the research. Says if he does not respond I think perhaps we just accept he is not ready at this time and wait for him to reach out to us again”*	Pattern evolved due
Thinking (philosophically)	Talking about/capturing	During exhibition phase	Was in relation to my own emotional response the artworks, and the project	*“Am I doing enough to support them? Am I forcing collaboration?”*	Pattern evolved due

Facilitating – Developing a theme

Clusters	**Candidate themes**
Cluster 1 - Developing solutions, Spaces (empty versus curated)	Facilitating curating by inviting new voices into hospital spaces (expansiveness?)
Cluster 2 - Boundaries, Involvement & inclusivity (role)	Professional curating by practicing flexibly (artfulness?)
Cluster 3 - Self-questioning, Thinking (philosophically)	Philosophical curating by being person-centred (care-fulness?)
Not clustered	Covid, Support (for me)

Appendix D VisualBeats Protocol

VisualBeats. Piloting patient-centred curating as a complementary way of researching the experience of a music making programme for young adults hospitalised with cancer

VisualBeats

- **This protocol has regard for the HRA guidance**

RESEARCH REFERENCE NUMBERS

IRAS Number 269754

PROTOCOL VERSION NUMBER AND DATE

Version: 1.0 Date: 01.10.2019

SPONSOR

The Royal Marsden NHS Foundation Trust

VisualBeats. Piloting patient-centred curating as a complementary way of researching the experience of a music making programme for young adults hospitalised with cancer

Version: 1.0 Date: 01.10.2019

RESEARCH REFERENCE NUMBERS

IRAS Number:	269754
SPONSORS Number:	CCR5182
FUNDERS Number:	Youth Music Programme Grant 6919 B9S2

STUDY SUMMARY

Study Title	Visual Beats. Piloting patient-centred curating as a complementary way of researching the experience of a music making programme for young adults hospitalised with cancer
Internal ref. no. (or short title)	Visual Beats
Study Design	Pilot/proof of concept
Study Participants	Young adult inpatients
Planned Size of Sample (if applicable)	14-42 (7 groups of 2-6 inpatients)
Follow up duration (if applicable)	N/A
Planned Study Period	January 2020 to February 2021
Research Question/Aim(s)	How do curatorial methods further understanding of the music-making experience for young adults hospitalised with cancer? A feasibility study.

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	FINANCIAL AND NON FINANCIALSUPPORT GIVEN
The Royal Marsden NHS Foundation Trust	Researcher's salary and 75% University of Southampton academic fees (part-time PhD year 3 as of 2019-2020)
The National Foundation for Youth Music	Funding for delivery and evaluation of the Youth Music Programme under the Grant 6919_B9S2

KEY WORDS: Cancer, arts-in-health, patient-centred, co-design, curating, proof-of-concept, pilot, feasibility

LIST of CONTENTS

STUDY PROTOCOL

1 BACKGROUND

In addition to physical symptoms and side effects experienced during cancer treatment, the psycho-social experience for young adults in hospital includes feeling less autonomous, more isolated and increasingly lonely (Bultz, 2016, Bours et al, 2016, Grinyer, 2007, Woodgate, 2006). Addressing the physical and psycho-social effects of treatment is recommended as a research priority by these young adults (Aldiss et al, 2019) and the multi-disciplinary team's focus when pursuing excellent person-centred cancer care (Care Quality Commission, 2016, Dougherty et al, 2015).

Interventions that encourage creative expression and social support for the people taking part are increasingly considered useful additions to a portfolio of holistic care (All-Party Parliamentary Group, 2017, Wright & Pascoe, 2015, Swindells et al, 2013). Participatory arts activities within healthcare spaces impact positively on both psycho-social and physiological health and well-being of both those taking part, and other stakeholders such as relatives and staff (McNeill et al, 2018, Sadowski, 2017, Stephens, 2017, Daykin et al, 2016, Wilson et al, 2016, Chatterjee & Camic, 2015, Salzano et al, 2013, Ingeberg, et al, 2012, Van Westrhenen & Fritz, 2012, Renton et al, 2012, Lyubormirsky et al, 2011, Moss & O'Neill, 2009, Department of Health, 2007, Suter & Baylin, 2007, Staricoff et al, 2004).

Whilst the evidence base suggests that music-making is the most effective of these arts-in-health activities (MacDonald et al, 2012), it is not clear why that is the case (Warran, Fancourt & Wiseman, 2018). The processes responsible for the ensuring the interventions are successful are not well understood, and more rigorous evaluation is encouraged (Public Health England, 2016). Feasible, innovative ways of further interrogating the process of these programmes and connecting wider audiences with the new knowledge being produced are warranted (All-Party Parliamentary Group, 2017).

Curators are uniquely positioned to provide interventions that bring artists, places and publics together creatively, experimentally, and collaboratively (O'Neill, Wilson & Steeds, 2016). "Patient-centred curatorial practice" is an arts-based research approach exploring how healthcare based curators engage those in hospital with the arts in new ways (Wecker, 2019, Barone & Eisner, 2006, Cramerotti, Knowles & Cole, 2007).

This study uses patient-centred curatorial practice ("co-curating") to further understand the process and experience of an evidence-based music making programme for young adults hospitalised with cancer. As a pilot project it involves the two phases of exhibition and evaluation. It aims to evaluate if these methods can provide complementary knowledge concerning the psycho-social mechanisms involved in the participatory arts programme in which it is embedded. It also hopes to empower and activate the individuals and groups taking part through these means (Snow, 2019, Bartlett, 2015).

The wider participatory arts programme "VocalBeats"

The young adult participants in this pilot study are also taking part in individual and group artist/musician led music making sessions funded by Youth Music at both the Royal Marsden and Royal Brompton and Harefield NHS Foundation Trusts. Outcomes of the wider programme are being separately evaluated quantitatively using skills development and well-being tools provided by the funder.

1 RATIONALE

To pilot the ways collaborative exhibition-making can aid further understanding of the mechanisms involved in a hospital-based participatory arts programme that impact on those taking part and other stakeholders.

2 THEORETICAL FRAMEWORK

As a "live" method of enquiry (Back & Puwar, 2012), curating is acknowledged to explore social science questions in dynamic ways (O'Neill, Wilson & Steeds, 2016, Krzys Acord, 2010, Obrist et al, 2003), by involving public encounters involving creative collaboration, and exhibiting (Puwar & Sharma, 2012). This can generate new ways of thinking, talking and engaging with the experience of being a young person with cancer (Lambert, 2016). To date however, collaborative curating has not been used to further understand the experience and mechanisms involved in participatory arts practices for young people with cancer.

Experience-based co-design (EBCD) is a method that embeds the experience of young health service users into the design of psycho-social support interventions intended for their use (Weston et al, 2018). Successful strategies for encouraging engagement through these means include co-design workshops with popular culture references, communication tools, and design methods (Clarke et al, 2017).

This pilot study will blend collaborative curating with experienced-based co-design. Embedded within a wider programme of arts participation activity, it will not test a hypothesis (Leon et al, 2011). Instead it will involve collaborative creative and improvisatory practice as an arts-based research approach (Rolling, 2011). It will gather and interpret findings iteratively (Lambert, 2018), and examine its feasibility as a complementary research approach. Finally, it will consider its future use on a broader scale, alongside other research activity, and with different patient groups.

3 RESEARCH QUESTION/AIM(S)

How do curatorial methods further understanding of the music-making experience for young adults hospitalised with cancer? A feasibility study.

3.1 Objectives

To co-design and co-curate an exhibition about the experience of a hospital-based music-making programme for young adults with cancer, to evaluate its effect on the stakeholders involved, and its feasibility as a complementary research method.

3.2 Outcome

That the understanding of being hospitalised creative young adults with cancer is explored through co-designing and evaluating a public-facing exhibition of their experience.

1 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

The wider programme of arts in health practice into which the co-design groups and exhibition will be embedded offers artist-led music-making for young adults aged 18-25 hospitalised with cancer or cardiovascular disease at the Royal Marsden and Royal Brompton and Harefield NHS Foundation Trusts. Commissioned in partnership with a national charity and running over two years, that programme encourages musician-in-residence led making, learning and rehearsing music with children and young people, and has shown to positively impact on participants' health and well-being (National Foundation for Youth Music, 2017, Selfhout et al, 2009).

This pilot study is designed by the research problem it seeks to explore. That is the potential invisibility of the processual mechanisms responsible for affecting a positive impact the wider music-making programme has. As an exploratory co-curatorial approach, it will embrace creativity and experimentation to seek this new knowledge (Wells, 2007). Qualitative in nature and framed within a social science philosophy (Lambert, 2018), the design selected is the best fit for this study because it asks "how" and "why" questions and because as with much arts-in-health research, the phenomena involved cannot be separated from the context (Bleakley, 2015).

Using an EBCD approach (Bate & Robert, 2006) within a qualitative arts based research framework (Creswell, 2009), the study will employ an iterative process where the young adults with cancer are fully involved in the development of the exhibition via user focused design workshops and user experience testing. The participants will also be involved in, and will continue to be involved in, the design of the evaluation methodology.

The study consists of two phases. **Phase 1 is the design phase and Phase 2 is the evaluation phase.** Those who consent to take part will join six months of researcher-led co-design sessions in preparation for a public exhibition over the course of a further four months. After this the process of designing the exhibition, and audience/stakeholder feedback from these, will be evaluated.

Led by a post-graduate researcher and hospital curator, the co-design group sessions will be held in a meeting room on the young adult inpatient unit at pre-assigned times. Group participants will be invited to methodically share their experience as developing artists/musicians through a multi-media art exhibition physically representing what might be a similarly curated in a social media feed (Thompson & Reilly, 2019). They will be encouraged to consider characteristics of other music-themed exhibitions such as the sharing of communal experiences and familiarities (Fairchild, 2012), and to share artefacts including written lyrics, sound recordings, and videos.

All practical steps for putting on an exhibition including those particular to each setting and audience will be considered in the six sessions (see below). Held once per month prior to, and in the month after, the exhibition the co-design groups will comprise between two and six participants – numbers considered appropriate to ensure "cultural competence", optimal data saturation, and variability in discourse in a difficult to reach group such as those receiving inpatient cancer treatment (Ochieng et al, 2018, Guest et al, 2006).

Schedule of co-design sessions:

Session 1: “Starting Off”

Session 2: “Inspirations and Ideas”

Session 3: “Ideas to Reality”

Session 4: “Planning and Evaluating”

Session 5: “Promotion and Documentation”

Session 6: “Putting the Show Together”

Session 7: “After the Event” reflects on the impact of the exhibition

George, A. (2015). The Curator’s Handbook: Museums, Commercial Galleries, Independent Spaces. London, Thames & Hudson.

Moderated by the researcher, the groups will be encouraged to agree the most optimal audio, textual and visual material for the show, and as the exhibition plan develops. A coaching style will be adopted by the moderator characterised by belief in the capacity of the individuals taking part, active listening, paraphrasing, and asking questions that mediate thinking (Netolicky, 2016). Inspired and spontaneous activities and discussions will be given priority (Barrett & Bolt, 2010).

Following the co-design group sessions, aggregated material will be installed and displayed as a four-month long exhibition co-curated with group participants, intended to offer new connections with new audiences (Latour, 2007). Being held at the home hospital, the exhibition audience will be made up of other stakeholders including peers, spouses, family, friends, hospital staff and visitors.

During the exhibition period, these stakeholders’ perceptions and responses will be sought through a “chalk board” that can be photographed (for data collection) and cleaned/reset periodically. This approach is effective as an extension of a previous exhibition where feedback also aimed to capture perceptions of and about people with cancer (Lambert, 2016).The Guiding Arts-Based Research Assessment (GABRA) meta-framework may be adopted for formally assessing the impact of the exhibition using normative, substantive and performative criteria (Lafreniere & Cox, 2013), and comparisons made with other audio-visual research exhibition formats (Barone & Eisner, 2012, Knowles & Cole, 2007).

Added to the dataset, moderator/curator field notes will be made of tensions, mistakes, revelations, decisions and compromises (Puwar & Sharma, 2012) captured during all research phases. Notes derived from the researcher’s immersion in the co-design groups will be “hidden” by being captured immediately afterwards, so as to avoid the negative influence on participant behaviours that “open” note taking may provoke (Emerson et al, 1995). The notes will be written in the third person, describing from varying points of view, and include capturing direct and indirect speech by the anonymised participants. This approach is appropriate as it encourages consensus on accuracy of recall, perception of change over time, and also because the researcher himself is not present during the delivery of the wider music programme (Bartlett & Milligan, 2015).

On enrolment in the study, participants will be assigned unique identification codes and their data stored in a linked anonymised Registration Form. Anonymised data will be managed in NVivo software provided by the University of Southampton, for use at The Royal Marsden NHS Foundation Trust. Textual data will be transcribed verbatim and other (such as visual) data compiled accordingly (Pink, 2012). Familiarisation, coding, analytical frame-working, and the development thematic analysis will happen in real-time, throughout the course of the study.

The aim of the data analysis will be to provide expanded analytic generalisations, rather than to try to extrapolate “particularised” probabilities (Barlow et al, 2008). Any developing themes will be shared in the co-design groups by the researcher to member check any assumptions, conjoining, or comparative analysis that may be proposed. Framework Method may be used to provide clear steps to follow and structured outputs of any summarised data, being useful for multi-disciplinary research in healthcare were those inexperienced in qualitative analysis need to obtain a holistic, descriptive overview of the entire data set (Gale et al, 2013).

All hard copy research documents will be kept by the researcher in a locked cupboard in a Royal Marsden NHS Foundation Trust office with security access, and only available to the research team. All digitised data will be stored as password-protected folders at the Royal Marsden NHS Foundation Trust, with only the immediate study team having access to these passwords. Any identifiable data will be kept for 3 months and anonymised data for 5 years after the study has ended.

1 STUDY SETTING

The study setting is The Royal Marsden NHS Foundation Trust’s Sutton hospital site, where the young adult patient population are cared for.

The researcher is employed part-time as Arts Officer at The Royal Marsden NHS Foundation Trust and part-time Health Sciences PhD student at the University of Southampton. The study’s progress will be overseen by the researcher’s supervisory team at the University of Southampton, and the project steering group at The Royal Marsden NHS Foundation Trust. The research will be plotted through three researcher-led academic publications in peer-reviewed journals, satisfying the requirements of a PhD at the University of Southampton.

2 SAMPLE AND RECRUITMENT

2.1 Eligibility Criteria

Patients over the age of 18 at any disease stage and in any capacity will be eligible. Those under the age of 18 will be excluded from this study, but not the wider arts programme in which it is embedded.

2.1.1 Inclusion criteria

- 18-25 years of age
- A patient at The Royal Marsden NHS Foundation Trust’s Sutton hospital site
- Have had involvement in the wider VocalBeats project
- English speaking (able to contribute to co-design group discussions)

1.1.1 Exclusion criteria

- People considered too unwell (self-report or in consultation with clinical staff)
- Those without the capacity to give full informed consent

1.2 Sampling

The proposed participants for this one-centre study will be young adults with cancer aged 18-25 being treated at the Royal Marsden NHS Foundation Trust. Participants will be screened against criteria prior to inclusion and exclusion. Each participant will be encouraged to join the study for a minimum of one co-design group discussion, and will be free to withdraw at any point without giving a reason. It will not be necessary for participants to commit to the study in its entirety and individuals at all stages of cancer treatment are invited, from diagnosis to end of life care.

Each participant will be expected to attend at least one 60 minute workshop (1 hour in total). Participants will be reminded at regular intervals that they can withdraw from the project at any time and will not have to attend again, or contribute anything they do not want to. Allowing for a changing group membership, and the sequential study design, is considered appropriate for a researcher working independently (Creswell, 2009).

1.2.1 Size of sample

The maximum number of qualitative data producing inpatient participants will be 42 (7 groups of 2-6 people). Controlling feedback from other stakeholders and the wider public around the exhibition will be open-ended, and data from this source will be aggregated, shared for discussion and included in the full qualitative data set by consensus.

1.2.2 Sampling technique

The study will be open to all eligible young adults in the inpatient unit settings as agreed with the safeguarding leads that in some way take part in the wider programme, available at the time and willing to take part. This purposive sampling approach is designed to ensure the study is informed by “key informants” who are typical (Quinn-Patton, 2002) and is based on convenience.

1.3 Recruitment

No payments or incentives will be used to recruit participants in this study. The participatory arts workshops in which the study will be embedded take place over two years as per the wider funding arrangement secured. The wider programme is open for 24 months starting September 2019. Participants in this embedded study will be able to start at any point during the wider programme.

These potential participants (inpatients involved in the wider music-making programme) will be invited by the research team to the full series of the co-design groups. Once identified, information about the study will be distributed by the researcher, by hand and in printed form to potential participants. The researcher will also meet with any new potential participants before a co-design group, to gain their consent to take part.

1.1.1 Sample identification

Potential patient participants will be identified from inpatient lists and approached with permission from the Youth Support Coordinator at The Royal Marsden NHS Foundation Trust, who will monitor the well-being of those taking part throughout. Extra consideration will be given to any feelings of obligation that other young adult inpatients or musicians-in-residence may feel towards participating in the study. The Youth Support Coordinator will be on hand to discuss this throughout.

7.2.2 Consent

Participant Information and Informed Consent sheets detail the nature of the study and what it involves. Participants will be given reasonable time to consider whether they would like to take part, and an opportunity to question the researcher before agreeing to participate. A copy of the signed Consent Form will be given to the participants agreeing to take part, with the original signed form retained at the site.

No deception will be involved in this study. The researcher has no reason to believe participants may not be able to give full informed consent to take part. Consent will be obtained again from participants once they create any audio- visual products, or once they see how these are going to be used, such as a draft of a publication, or proposed material for exhibition.

At all stages, deliberate, collaborative consideration will be devoted to the question of what (if any) personal information enters the public space of the exhibition. The public use of personal history, diagnosis or other clinical details, or even the name of the artist, will be thoroughly discussed before the work enters the exhibition. The goal will be neither to unduly expose nor to summarily silence the participants, but rather to collaborate and set a tone that is appropriate for the circumstances (Vick, 2011).

Although copyright is not an ethical issue, it is important to consider it in relation to visual products generated as part of a research project. In the case of this study it will also be agreed at group level (through protocol) who owns any audio-visual products created during the project, and who decides how they are to be used and represented. Integrity around consent to obtain research data from members of the public engaged through the exhibition will be as per the National Coordinating Centre's Manifesto for Public Engagement, which the University of Southampton has endorsed.

Whilst it will be made clear that participants are free to withdraw from the study at any time for any reason without prejudice to future care, and with no obligation to give the reason for withdrawal, that anonymous data cannot be withdrawn after submission. Participants will be asked to give consent for the (anonymised or otherwise) outcomes of the study to be published or be publishable through the exhibition format and three peer-reviewed journal articles during the PhD candidature. Written materials will be read and signed approval obtained from participants, including the journal publications and any exhibition-related published material.

1 ETHICAL AND REGULATORY CONSIDERATIONS

Health Research Authority (HRA) has reviewed and approved the research. The researcher will ensure that the study is conducted in accordance with the principles of the Declaration of Helsinki. No recruitment will take place until the appropriate permissions have been granted. It will follow all standard operating procedures, policies and local R&D management guidance for the NHS and overall governance is provided by The Royal Marsden NHS Foundation Trust as main sponsor.

1.1 Assessment and management of risk

Employed as Arts Officer at the Trust and funded PhD student at the University of Southampton, the researcher as Study Co-ordinator will take overall responsibility for day to day management of risk during the study, leading on patient recruitment, ethical approval, qualitative data capture through the co-design groups, data analysis, and study write up. Along with the Chief Investigator who is his line manager, he also takes overall responsibility for day-to-day running of the study, assessments of study progress, and data governance.

In preparation for this role, the Study Co-ordinator has completed a Research Methods in Health Practice Postgraduate Certificate at the University of Bath. He also brings experience gained as an academic psycho-social scientist (BA Hons/PG Cert), twenty years of clinical nursing (BSc Hons), health service project management (MBA) and five years postgraduate arts and curating practice (Grad Dip). As a PhD student, his supervisory team includes an Associate Professor in Health Sciences at the University of Southampton.

As with any public-facing arts critical arts practice, this research may provide the aesthetic and affective conditions for social disruption, indeed it has been suggested that it may not be possible to do publically engaged research without some degree of psychological discomfort (Lambert, 2018). A certain degree of emotional labour will be necessary on the part of the researcher and other participants to process design group narratives and arts practice. The impact of this will be carefully considered through group, self and relational reflexivity (Malthouse et al, 2014).

As the activities offered are of a supportive nature, the risk of any inconvenience or distress occurring to participants is considered to be low. The researcher's role as Study Co-ordinator in this setting will be significant, where good levels of group leadership and interpersonal skills are required to moderate the co-design groups successfully and to further minimise this. Any positionality issues that may occur leading this research will be assessed throughout.

It is possible, and therefore risky, that these groups may be the first time the participants experience communicating with a researcher in a formal setting. A coaching conversational style with strength-oriented questioning that encourages positive group agency and shared narratives (Zeilig et al, 2019, Mathieson & Stam, 1995) will be utilised to minimise the risk of blurring the boundary with individual psychological support or therapy. The researcher's field notes will be an accessible and literal record of narratives and inferences being drawn from the research process. These notes will be used to inform any professional support that may be required.

Formal links and referral pathways to psychological support services will be in place throughout the study as required. A detailed Participant Information Sheet clarifies the scope and boundaries of discussions and the researcher is clear about the limits of his role scope, and when to report an adverse event (AE) such as referral to psychological support services. As per research at any NHS location, any AEs will be reported from consent until 30 days after the last study procedure.

Already considered vulnerable on account of their early stage of adulthood with complex health needs, it will also be made clear that parents, guardians and/or spouses are welcome at on-boarding discussions led by the researcher, supported by the Youth Support Coordinator, and overseen by the Adult Safeguarding Lead. For co-design group sessions however, parents, guardians and/or spouses will be welcome to settle participants but then be asked to leave, to ensure homogeneity of data reflects the research aims.

Additionally, the project steering group made up of key organisational members will meet periodically to ensure that the research is running well practically, and that participants are also “practicing well” as artists. This will include an assessment of their labour as socially engaged art practitioners and discuss any intellectual property issues and risks that may arise. Prior to the beginning of the study the project steering group will agree a support “menu” that clarifies where participants can turn with any practice-related rather than heath or academic concerns (Naismith, 2019).

Overall it is hoped that the proposed research experience will be transparent, inclusive, collaborative and safe for all, with no adverse events. Where they do occur, the researcher as Study Co-ordinator will review whether an event is classed as a serious adverse event (SAE). All SAEs will be reported within 24hrs of knowledge to the Chief Investigator and followed up until resolution. Any other significant safety issues identified during the course of a study will also be reported in an expedited fashion to the Chief Investigator in the first instance. NHS insurance and indemnity will apply.

1.1 Research Ethics Committee (REC) review & reports

Before the start of the study, approval will be sought from a REC for the study protocol, informed consent forms and other relevant documents. Substantial amendments must be reviewed and approved by REC and HRA. Non-substantial amendments are reviewed by the HRA only. All amendments must receive confirmation of capacity and capability from the participating site before implementation. Any amendment must be reviewed by CCR (sponsor) prior to submission to regulatory authorities.

All correspondence with the REC will be retained, and the Study Co-ordinator and Chief Investigator will produce reports as required, notifying the REC of the end of the study. An annual progress report (APR) will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended. If the study is ended prematurely, the Study Co-ordinator and Chief Investigator will notify the REC, including the reasons for the premature termination. Within one year after the end of the study, the Study Co-ordinator and Chief Investigator will submit a final report with the results, including any publications/abstracts, to the REC.

1.2 Peer review

This protocol has received expert input from various support departments within the Royal Marsden NHS Foundation Trust. It has passed peer-review at the University of Southampton (Faculty of Health

Sciences), and is peer reviewed as part of the sponsorship approval process by the Royal Marsden and Institute of Cancer Research (ICR) Committee for Clinical Research (CCR). The CCR is comprised of senior staff within Royal Marsden and ICR with significant expertise in clinical research. The CCR approval process consists of expert peer review by a consultant-level clinician and a statistician who are both independent of the study team.

1.1 Patient & Public Involvement

This study forms part of a larger 2-year grant looking at music making for people with cancer. Patients with cancer, carers and staff took part in focus groups to design the research questions at the start of the grant and approved all study designs and measures. Patients and public also actively took part in designing recruitment for the study, and will help to disseminate results from other completed phases of the grant.

1.2 Regulatory Compliance

Before enrolling patients into the study, the Study Co-ordinator and Chief Investigator will apply for R&D Confirmation of Capacity and Capability from the site management organisation, HEI or NHS Research & Development (R&D) as appropriate.

For any amendment that potentially affects a site’s R&D Confirmation of Capacity and Capability, the Study Co-ordinator and Chief Investigator will confirm with that site’s R&D department that R&D Confirmation of Capacity and Capability is ongoing (note that both substantial amendments, and amendments considered to be non-substantial for the purposes of REC may still need to be notified to NHS R&D).

This adult-only qualitative study will be conducted in compliance with an agreed protocol, standard operating procedures, policies, local R&D management guidance, Good Clinical Practice including the UK Policy Framework for Health and Social Care Research and other applicable regulatory requirements. The Study Co-ordinator has undertaken GCP and consent training at the Royal Marsden NHS Foundation Trust. All research documents will be available for monitoring, audits, and regulatory inspection(s).

1.3 Protocol compliance

Accidental protocol deviations can happen at any time. If that occurs they will be adequately documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately. Deviations from the protocol which are found to frequently recur are not acceptable and will require immediate action.

1 DISSEMINIATION POLICY

1.1 Dissemination policy

All publications associated with the study will receive final authorisation from the University of Southampton supervisory team who will also be involved in reviewing drafts of the manuscripts.

The proposed structure of the three PhD publications derived from this study will be as follows:

Publication 1 - A focused literature review paper of the topic being investigated followed by the theoretical basis for the research approach being proposed. Aim to be published within the Journal of Visual Culture (or similar) during the first 3 months of study launch, to a critical curatorial audience.

Publication 2 - A methods paper that reflects on robustness of the research design, using illustrative examples of data collected so far. It is a professional development paper aimed at an arts-in-health scholarship, published within the journal Arts In Health (or similar) during 6-12 month period following study launch.

Publication 3 – A results paper that discusses the impact of the exhibition, any limitations and possible directions for future (post-doctoral) research. It is aimed at a wider social and health sciences scholarship. Publication is sought within the Journal of Psychosocial Oncology Research & Practice, the journal of the International Psycho-Oncology Society (or similar) during the 12-18 month period following study launch.

The study protocol, full study report, anonymised participant level dataset, and statistical code for generating the results will be made publicly available.

1.2 Authorship eligibility guidelines and any intended use of professional writers

The sponsor owns the data arising from the study, and the University of Southampton (as supporting body) is acknowledged as having review and publication rights of the data from the study. As PhD researcher, Benjamin Hartley (Study Co-ordinator) will be granted first authorship on the PhD publications derived from this study, and all other study reports.

2 REFERENCES

11. APPENDICIES

11.1 Appendix 1- Required documentation

N/A

11.2 Appendix 2 – Schedule of Procedures (Example)

13.3 Appendix 3 – Amendment History

Appendix E VisualBeats Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Study Title: VisualBeats. Piloting patient-centred curating as a complementary way of researching the experience of a music making programme for young adults hospitalised with cancer

Researcher: Benjamin Hartley

You are invited to take part in the above research study because you have participated in a Vocal Beats music-making session whilst in hospital. To help you decide whether you would like to take part in this study, it is important that you understand the research and what it will involve.

Please read the information below carefully. You can ask questions if anything is not clear, or if you would like more information before you decide if you would like to take part in the research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

We know that cancer and its treatment can affect a person’s physical and mental health. The wider Vocal Beats music programme is designed to enable people with cancer to experience less stress and loneliness and improved wellbeing whilst developing their ability to make music.

In this study we would like you to participate in organising an exhibition related to the Vocal Beats music programme.

To achieve this, you and a number of other people aged 18-25 who took part in Vocal Beats will be invited to join exhibition planning groups led by a researcher. The purpose of these discussion groups will be to plan (or “curate”) the exhibition, which will be held within a public area at The Royal Marsden hospital, and to provide feedback after the exhibition has taken place.

In the groups you will agree on the choice of audio and visual material for inclusion in the exhibitions. This material might be your own, or that of your peers on the programme.

Asking you to take part in the exhibition planning process in this way is known as “co-designing” and being “co-curatorial”. The overall aim of the research is to consider whether this method – using small groups and exhibitions to show your music-making story - enables others to understand and learn new things about your experience of making music whilst being a young adult living with cancer.

Who is organising and funding the research?

The research is led by the Royal Marsden NHS Foundation Trust. Professor Theresa Wiseman is the Chief/Principal Investigator for the study. The researcher and Study Co-ordinator is (Ben Hartley), a PhD student registered with the University of Southampton, and Arts Officer at the Royal Marsden hospitals. Ben’s university fees are jointly funded by the hospital and Ben himself. The musical activities being discussed in the groups, and the sessions themselves, are jointly funded by the hospital and Youth Music (a national charity).

Why have I been asked to participate?

You have been invited to take part in this research because you are a young adult (aged 18-25) who has taken part in the wider Vocal Beats musical programme.

What will happen to me if I take part?

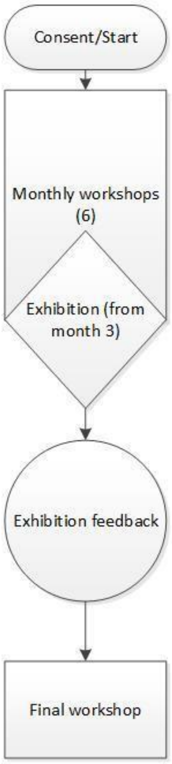
If you take part you will be invited to one or more monthly discussion groups (up to a maximum of seven groups). In each hour-long group, up to six young adults will be discussing, with the researcher, how to put together an exhibition of the videos and recordings of music made by you and/or your peers. The groups will meet in a dedicated room at the Royal Marsden hospital in Sutton.

You will not have to provide any footage or recordings of your own music-making to take part in the exhibition, and you will not have to perform music to take part in the groups. There are many things you could do to help put the exhibition together, such as agreeing written information that is published for the exhibition, or discussing technical points about how the material could be exhibited.

It may be that live music performances can form part of the exhibition but, as this is not always possible to arrange in hospitals, it is not essential. Mostly, the exhibition will be about telling your and your peers' story of music-making.

During the exhibition the researcher will gather feedback from the audience. Afterwards, he will invite you to come back and hear what the audience said, and encourage you to comment on it.

The researcher will lead all the sessions. He is not a musician, but he will be interested in your experience of making music. He will audio record the group sessions and will make anonymised notes about what was said afterwards. This is a plan of the research:



In the first six sessions, the researcher will suggest what needs to be discussed in order to curate the exhibition. He will invite you to consider producing and sharing any recordings, videos or notes you may have made whilst making music in hospital. The group will be invited to view/listen to this material and comment on it, and to discuss how it should be displayed in the exhibition.

After the third session, the exhibition will start to be put together by the researcher and any other group members who are willing to assist. More material can be added in relation to the fourth, fifth and sixth sessions. The exhibition will be on display for between three and four months in all. Patients, visitors and the general public will see the exhibition content, and be invited to feed back their thoughts to the researcher through a message board.

After the exhibition, the researcher will invite all group participants back to review what the public have said, and to feed back the overall experience of taking part. If you take part in an earlier group or groups, but not the exhibition, you will still be invited to let the researcher know what your experience was like.

Are there any benefits in my taking part?

There may be no direct benefit for you to take part in this research. However, your contribution may help improve people understand the experience of being a young adult making music whilst being treated for cancer. Furthermore, it would provide information on whether designing and evaluating the exhibition may have contributed to this in any way.

Are there any risks involved?

Taking part in the study will be over and above standard care, and no treatment will be withheld during any part of the study. We do not anticipate that you will experience any unpleasant effects from your involvement in the research. However, some people can find talking about their cancer experience raises sensitive issues. The wider team involved in this study are healthcare professionals who are used to speaking about these issues. They will not talk about anything you do not wish to talk about. If you find any aspect of your experience too difficult, we will provide you with details of where you can access the support you need.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee (REC), to protect your interests. The study has been reviewed by the Leeds West REC. It has also been reviewed by The University of Southampton Ethics and Research Governance Online (ERGO), and the Royal Marsden NHS Foundation Trust/Institute of Cancer Research Committee for Clinical Research (CCR).

What data will be collected?

We need to provide you with information about how your data are processed for transparency purposes under the new General Data Protection Regulation, or GDPR as it is more commonly known.

The Royal Marsden NHS Foundation Trust (“the Trust”) is the sponsor for this study. Any audio or visual material you contribute to this study is called “data”, and The Trust will act as the “data controller” for this study. This means that The Royal Marsden is responsible for collecting and looking after this material, and using it properly.

Material will be collected by the researcher using an encrypted audio recorder, and the recordings will be stored by him in electronic password protected folders at the Trust. Recordings will be transcribed into words by the researcher and anonymised, and only accessible to the researcher. The recordings will be kept for the duration of the study then destroyed by the researcher.

We will keep identifiable information about you for 3 months after the study has finished and anonymised data for 5 years after the study has finished. If you withdraw from the study, we will keep the information about you that we have already obtained. You can find out more about how we use your information here https://www.royalmarsden.nhs.uk/privacy

The researcher may use the Trust's "NVivo" software to analyse the anonymised data, such as quotes or images.

When you meet the researcher to provide your consent to take part, you will be asked if you wish to be associated with any quotes, images or performances that are used. Even if you do not wish to remain anonymous, a final check will be made at each stage of the study to ensure you are happy with the level of anonymity being used.

Individuals from The Trust, University and regulatory organisations may want to check the accuracy of the research study such as by auditing the data collection process. If this happens, your anonymity will be guaranteed.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential, unless you request otherwise. Any material you provide for the exhibition (such as videos of performances, lyrics, recordings) will be anonymised unless you agree otherwise, as per the consent form you will be invited to sign, and re-sign as necessary or as requested.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, please let the researcher know. You will need to sign the consent form to show you have agreed to take part.

What happens if I change my mind?

You have the right to change your mind and withdraw at any time without giving a reason and without your routine care being affected. If you withdraw from the study, we will keep the information about you that we have already obtained for the purposes of achieving the objectives of the study only.

What will happen to the results of the research?

Over the course of the group sessions and exhibition, the researcher will write one or more research papers about the entire project. These research papers, like the exhibition, may benefit from showing examples of the music-making that has taken place or providing direct quotes from the discussions.

Your personal details will remain confidential unless you have agreed otherwise. The content of any reports or publications will not include information that can directly identify you without your specific consent. Anonymised extracts and quotes from the research may be used in presentations or other forms of communication relating to the study, and the same confidentiality rules will apply when this happens.

Where can I get more information?

If you would like further information about this study please contact the researcher and Study Coordinator Ben by emailing Benjamin.Hartley@rmh.nhs.uk . Ben works within the Applied Health research team and can also be contacted by telephone through the Trust switchboard.

What happens if there is a problem?

If you have concerns about any aspect of this study, you should speak to Ben, the Study Co-ordinator, who will do his best to answer your questions. If you would like to be referred to other services for support, Ben can also ensure that this is done. If you remain unhappy or have a complaint about any aspect of the research, you can also contact the Chief Investigator

You can also get in touch with the Patient Advice and Liaison Service (PALS) by phone, email or in writing. In Sutton, PALS is in the main entrance and you can call them on 0800 783 7176.

Thank you

Thank you for taking the time to read this information sheet, which is yours to keep. If you are interested in finding out more about taking part please let Ben the Study Co-ordinator know. When you meet Ben, and if you decide to participate, you will be asked to sign a consent form and given a copy of the form to also keep for your records. We will also keep a copy of your signed consent form within your medical record.

Appendix F VisualBeats Consent Form

The ROYAL MARSDEN
NHS Foundation Trust

CONSENT FORM

Study title: VisualBeats. Piloting patient-centred curating as a complementary way of researching the experience of a music making programme for young adults hospitalised with cancer

Researcher name: Benjamin Hartley

Participant Identification Number (if applicable*):*

Please initial the box(es) if you agree with the statement(s):

I have read and understood the Participant Information Sheet VisualBeats V 2 19.12.2019 and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand that my participation is voluntary and that I may withdraw at any time for any reason without my medical care or legal rights being affected.	
I understand that if I withdraw from the study, it may not be possible to remove the data once my personal information is no longer linked to the data.	
I understand that I may be quoted directly in reports of the research but that I cannot be directly identified (e.g. that my name will not be used).	
I agree to take part in the discussion groups/forums for the purposes set out in the participation information sheet and understand that these will be recorded using audio recording devices and written notes.	

I understand that my anonymity cannot be guaranteed in these discussion forums but that any information collected by the researchers will be kept confidential and other/all participants will be asked to keep the discussions confidential.	

Name of participant (print name)……………………………………………………

Signature of participant…………………………………………………………………

Date……………………………………………………………………………………….

Name of researcher (print name)……………………………………………………

Signature of researcher …………………………………………………………………

Date…………………………………………………………………………………………

Optional - please only initial the box(es) you wish to agree to:

I agree to my artwork and/or performances being photographed, recorded digitally, audio recorded, or otherwise duplicated for the purpose of publication, public display and exhibition.	
I agree that these audio recordings and/or images of or by me can be shown in the event of my no longer being treated at the Royal Marsden.	
I agree for a **chosen name** to identify me when my artwork and/or performances are duplicated for the purpose of publication, public display and/or exhibition. **Please state that chosen name here:**	

1 copy for participant, 1 copy for research study file, 1 copy for participant's medical notes

Appendix G Moderator’s notes (Workshop 2)

Observations as a moderator at the Visual Beats Workshop 2

16th September 2020

I had a few technical difficulties so joined 20 minutes in.

At that point one of the participants was expressing a fear that his work ‘won’t be good enough’ for the exhibition. He was given lots of reassurance that there wasn’t a ‘standard’.

There was a lot of good will in the workshop. They were polite and showed that they wanted to respect each other’s contributions; it felt as though there was an assumption on their part that the person who wasn’t there today would be making a central contribution and that they might produce music and images that would complement and support that. Neither took a lead of any sort, apart from when one said he thought that the exhibition should have a theme so that everything looked good together. I felt that maybe they weren’t comfortable in assuming a decision -making role and at that point preferred to listen and think separately. One described towards the end of the workshop that his mind was buzzing with ideas, so it may be that the workshop stimulated thoughts would lead to further, maybe more informal collaboration. It would be interesting to know whether the two did make contact afterwards. There was something, a hint of distance or a block that would need to be overcome I thought, for them to make more progress at working together.

In a conversation after the workshop with BH, I reflected that I have seen the same thing with my own children (18 and 22 years). There have been occasions where it would seem obvious that they should pick up the phone or message someone to resolve a problem but there seemed to be some unwritten social rule that I didn’t understand that you just shouldn’t do that. It would seem important to understand what these rules might be for the participants, to help get over the barriers that they cause.

I thought the workshop flowed well, they both contributed and seemed engaged. BH checked understanding about what had been said along the way. It stayed within the time limits, BH summarised the session and next steps, it came to a nice, logical end.

The ice breaker was a good idea but I reflected that if I had been asked that on the spot, it would have stumped me, I might have needed time to think about it!

Appendix H INNATE worksheet

ACTIVE INGREDIENTS WORKSHEET

The following worksheet is designed to help you to identify the active ingredients of your arts and cultural activity. Under each heading, you'll find questions that ask you to reflect on different ingredients, with space to write in the ingredients relevant to your activity – we've listed examples in italics to show you where to write. Please note that not every ingredient will be present within your activity, so you can write 'not applicable' or leave blank the boxes which aren't relevant.

PART ONE: PROJECT

ATTRIBUTES
What is the format of your activity?
Mode Describe the form in which the activity occurs *Virtual, in-person*
Synchroneity Explain the degree to which the activity or engagement occurs in real-time for participants *Real-time and asynchronous*
Activity level Tell us about the extent to which the activity requires active participation *Active/participatory*
Additional comments *Please use this space to write any additional comments in relation to the format of your activity*
How much (i.e., what 'dose') of your activity is received by participants?

Frequency Explain how often the activity occurs *Irregular (one-off)*
Duration Describe the length of one dose/exposure of the activity in time *Six months*
Maintenance Tell us over what time periods the activity continues *Short-medium term*
Additional comments *One-off dose over medium term*
What is the design (structural plan) of your activity? (This may or may not be adaptable.)
Structure Describe how the activity is organised in its delivery *Structured*
Guiding Explain whether the activity is taken in a particular direction to reach a goal or outcome *Guided (taught?)*
Project approaches Describe approaches or techniques employed within the activity that characterise it *E.g., mirroring, imitation, repetition*
Personalisation Explain whether the activity is designed to meet participants' needs or preferences *Reminiscence, storytelling, engagement with self*
Challenge Describe the intended level of difficulty of the activity, including whether the difficulty can be adapted across participants *Moderately challenging/stretching*
Goal orientation Tell us about whether the activity is directed towards a particular aim or ends, including who sets goals *Goal focused (a performance, target)*
Feedback Describe if and how evaluative information or reflections are included in the design of the activity *Formal, peer-led, and self-reflexive*

Additional comments *Exhibition planning is target activity/ exhibition is performance, feedback is multi-layered and uncontrolled (public)*
What is the artistic content of your activity? (Please note that artistic resources are included in the next question)
Genre Describe the primary branch of creative activity in which the activity(ies) is(are) categorised as well as any sub-categories *Music, gallery (visual arts)*
Multi-modality Tell us if the activity also draws upon a range of different art forms or disciplines in its delivery *Combined arts, poetry*
Activity type The kind(s) of activity(ies) included that define(s) the creative engagement *Art- and music-making, curating*
Themes Tell us if there is engagement with specific themes or subjects as part of the artistic content *Experiences (loosely)*
Additional comments *Cross-genre, multi-modal. Activities include solitary art- and music- making plus curating. Loosely themed.*
What resources (physical, conceptual, or informational) materials are used/employed in the delivery of your activity?
Activity consumables List activity resources that can be used up or depleted *Art materials, hardware, software.*
Props List items such as objects or furnishings employed within the activity *Exhibition spaces, hanging systems.*
Products List tangible outputs of the activity *Paintings, drawings, video recordings, poems etc*

Performances List intangible outputs of the activity (incapable of being perceived by the sense of touch) *Exhibition?*
Additional comments *Adjustable/pragmatic consumables and products. Activity needs organisational space/involvement.*
Are there any activities that are integrated into the arts/cultural activity? (NB. Collaborations or co-produced projects which form part of the project’s set-up shall be returned to in part three.)
Psychosocial support Describe any integrated professional techniques and/or resources designed to support mental health, wellbeing, experiences of psychological disorders and/or quality of life *Combined arts and techniques from coaching*
Allied therapies Describe any integrated therapeutic techniques that treat or manage physical disability, malfunction, pain or stress and tension via physical methods *N/A*
Health education Detail any integrated learning experiences designed to help individuals and communities improve their health by increasing their knowledge or influencing their attitudes *N/A*
Spiritual or holistic practice Detail any integrated experiences relating to religious, spiritual, or mind-body practices *N/A*
Socially engaged practice Describe any integrated programmes designed to engage with social issues or that seek social or political change *Integrating activism (as agency?) in an arts activity*
Additional comments *Is actually curating the socially engaged part?*
ENGAGEMENT
Do you employ/use/engage with any objects, actions, materials, or experiences that activate the senses as part of the activity (sensory stimuli)?
Sight (Vision) Explain if participants perceive objects or imagery by use of their eyes as part of the activity *Objects, images*

Hearing (Auditory) Explain if participants perceive stimuli by ear as part of the activity *Music, soundscapes*
Smell (Olfactory) Explain if participants perceive odour or scent through the nose as part of the activity *N/A*
Taste (Gustatory) Explain if the act of tasting food or drink is part of the activity *N/A*
Touch (Tactile) Explain if the body (i.e., hand, finger) is put in contact with something (i.e., an object or person) as part of the activity *In the making*
Additional comments *The sensory elements are split between the making and the exhibiting*
Do you employ/use/engage with any objects, actions, materials, or experiences that activate cognitive and/or creative processes as part of the activity (cognitive stimuli)?
Involvement of the imagination Explain if mental images or concepts beyond the senses are part of the activity *In the making*
Emotional stimuli Explain if there is something about the activity or aspects of it that brings about affective states of consciousness (feelings) *Positive or sad stimuli may elicit specific responses (making and exhibiting)*
Cognitive stimulation Explain if there is something about the activity or aspects of it that prompts mental processes of perception, memory, judgment, and reasoning (contrasted with emotional processes) *Problem-solving*
Aesthetic engagement Describe if participants engage with the activity through subjectively sensing something as beautiful *A focus on the exhibition’s aesthetic whole, audience response*
Pleasure Explain if there is something about the activity or aspects of it that brings about feelings of pleasure *Moments of enjoyment*

Participant choice Describe if participants make selections from a number of possibilities based on preference or under guidance as part of the activity *Guided choice with some autonomy*
Additional comments *Feels like it was a challenging activity*
Are any physical bodily motions or actions employed as part of the activity?
Proprioception (or kinaesthesia) Explain if heightened awareness of the body's position and movements is part of the activity, and whether it’s free or guided *N/A*
Movement Tell us if bodily movement is prompted by the activity *N/A*
Physical exercises Explain if any exercises are employed as part of the activity to promote bodily fitness and strength *N/A*
Additional comments *Please use this space to write any additional comments in relation to physical bodily motions or actions*

PART TWO: PEOPLE

SOCIAL COMPOSITION
Who are the people involved in the activity (social diversity)?
Presence of others Detail the number of people present and/or the size of the group that the activity entails *Small group and solo activities, public*
Shared attributes Describe whether individuals engaging together in the activity have characteristics in common *Same health condition (cancer), age, geographic location (of patients, some audience also)*
Distinct attributes Describe the diversity of individuals engaging together in the activity *Diversity was not discussed?*

Personal attributes Describe any other personal qualities that participants have which inform how they engage with the activity *Soft skills (creativity)*
Additional comments *Curating activity was themed in a way that engaged around shared attributes (creativity, cancer)*
Do participants have any previous experiences which are relevant to how they engage with the activity?
Activity experience State whether individuals engaging have previous experience(s) of the activity *For all this was the first time engaging with artform, though had been creative*
Health experience Outline whether individuals engaging have previous experience or knowledge of specific health conditions, healthcare in general, or health outcomes *Patients had prior experience of engaging in arts activities in healthcare contexts, facilitator had previous experience of healthcare, health outcomes*
Lived experience Tell us whether individuals engaging have subjective experiences relevant to who the activity is tailored for *Lived experience of cancer, being a patient*
Relationship to others Explain the kind of relationships the individuals engaging together in the activity have to one another *New group with some pre-existing friendships, carer present, no pre-existing facilitator relationship with patients*
Additional comments *Varied (unusual?) previous experiences of the patients involved in the activity*
Are there any social interactions (face to face or digital) <u>part of or integrated</u> into the activity?
Shared focus Explain if and how attention is given collectively to an object, activity, thought or person/people as part of the activity *Joint focus on the exhibition and mainly individual focus on items within the exhibition*

Shared activity Explain if and how participants cooperate or collaborate as part of the activity *Working together on the project and mainly working independently on artworks*
Social exchanges Describe the social elements of the activity itself that involve interaction with others *Discussing, turn-taking, peer learning, eye-contact*
Structured social time during activity Describe any aspects of the activity that encourage the formation of social relationships or socialising *Facilitated introductions, socialising over time*
Structured social time outside of activity Detail any planned time outside of the core activity delivery used to encourage the formation of social relationships or socialising *N/A?*
Communications Tell us if and how those in leadership/management communicate with participants in the lead up to and after the activity *Exhibition planning workshops including videocalls to discuss arrangements, follow up emails*
Additional comments *The social exchanges between patients that curating enabled were perfect for this age group?*
Are there social exchanges (face to face or digital) that that are not planned as part of the activity
Unstructured social time during activity Describe if space is provided during an activity for participants to informally socialise *Electronic communication of group.*
Unstructured social time outside of activity Detail if social time or social activities are shared between participants outside of the activity, without formal guidance *Indicated some met outside of the activity, while receiving treatment, and discussed it. Discussed artworks with music making team and support coordinator.*
Additional comments *Had not anticipated these unplanned/extraneous/spontaneous social exchanges between patients*
ACTIVITY FACILTATION

What kind of facilitation (i.e., the people who lead, guide, or facilitate the participant-facing aspects of the activity and not the administrative aspects) is employed?
Facilitator(s) Explain who facilitates the activity during its delivery and what form this facilitation takes *Leader-led as workshop leader and curating facilitator*
Co-production Describe if the activity involves actively including participants in the process of delivering and facilitating it *Embedded patient choice in the delivery of the activity, with patients taking ownership of facilitating the activity*
Number Detail the number of people who facilitate or lead the activity *A single facilitator*
Professionalisation Tell us about whether the person/people who facilitate the activity identify as professional(s) within their specific field/domain *Someone working as an arts-related professional (not a nurse)*
Training Explain if the person/people who facilitate the activity have professional training (i.e., domain-specific skills) *Professional artistic and health-related qualifications with professional development*
Consistency Explain whether facilitation changes or stays the same *Facilitator was same/consistent. What about YSC?*
Additional comments *The kind of leadership employed for the activity was vague – did I ever say I was a nurse previously? What did patients think of YSC's contribution to facilitation?*
If there is a facilitator, what experience do they bring to the delivery of the project?
Activity experience Tell us about the amount of previous domain-specific experience, knowledge, or skills the facilitator(s) have *Prior experience leading similar activities, knowledge of artistic/curating interventions*

Health experience

Outline the amount of previous experience or knowledge the facilitator(s) have in relation to specific health conditions, healthcare in general, or health outcomes

Prior experience working with the target group and with the specific health condition

Lived experience

Tell us if the facilitator(s) have firsthand experiences relevant to who the activity is tailored for

None, did not discuss being LGBTQ+

Relationship to others

Tell us if the facilitator(s) have any pre-existing relational experiences of engaging with participants

Completely new facilitator

Additional comments

The experience of activity leadership was defined in the PIS

In what style/manner is the activity is delivered and what artistic practice is drawn upon?

Technique

Explain whether the activity facilitator(s) draw on approaches or technical skills that are characteristic of one's domain-specific field

Curating

Personal attributes

Detail any additional qualities that the facilitator(s) bring to the activity that informs how it is delivered

Authenticity?

Values-directed focus

Explain if and how the facilitator(s) deliver the activity based on specific ethical values

Facilitator treats patients with respect, dignity & care / is adaptable, patient, caring, compassionate

Outcomes-directed focus

Explain if and how the facilitator(s) focus on health, educational, or aesthetic goals as part of the activity

Facilitator focuses on high-quality exhibition

Person-centred focus

Explain if and how the facilitator(s) consider participant preferences, needs, and values to deliver the activity

Facilitator makes group feel comfortable and at ease

Autonomy-directed focus

Explain if and how the facilitator(s) provide participants with autonomy as part of the activity

Facilitator provides opportunities for group to make self-directed choices and/or lead elements of the activity

Equality, Diversity, and Inclusion Explain if and how the facilitator(s) consider fair treatment and equal opportunities to deliver the activity *Actively ensuring equal opportunities to take part are created for those with mental or physical health conditions*
Safety Explain if and how the facilitator(s) consider the safety of participants in how the activity is delivered *Emotionally safe (being responsive to any psychological concerns)*
Tailoring Explain if and how the facilitator(s) personalise or adapt the activity to meet the needs of participants *Individualised and group-level tailoring including for specific health condition and disability*
Additional comments *The style/manner in which the activity is delivered -is CARING?*
Are there additional staff or other people that support, co-lead or are present at the activity?
Presence of volunteers List any unpaid staff who support or co-lead the delivery of the activity and explain what they do to support *Patients were volunteers (for research)*
Presence of healthcare professionals List any healthcare professionals and how they support or co-lead the delivery of the activity *Support coordinator supported the delivery of the activity*
Presence of others Detail whether there are any other staff or people and how they support, co-lead or are present for the delivery of the activity *None*
Additional comments *I need to think about the additional staff who supported or co-lead the activity*

PART THREE: CONTEXTS

SETTING

What circumstances, objects, and conditions make up the surrounding environment of the activity?
Location Describe the place where the activity is delivered *Workshops – on ward, online* *Exhibition - Indoors at a healthcare venue (hospital)*
Basic features Describe the functional aspects of where the activity takes place and how the room(s)/space(s) are arranged *ONE FOR EACH EXHIBITION SPACE* *ventilation, temperature, lighting, acoustics, facilities, furniture, chairs spacing*
Attractiveness Explain whether the environment of the activity is perceived as beautiful, attractive, or pleasing to the eye. Note any modifications made. *Functional vs beautiful, decorating rooms with materials, changing digital backgrounds*
Situation Outline the geographic and/or socioeconomic features of where the activity takes place *Workshops - virtual spaces* *Exhibition - Patient/public waiting areas. DESCRIBE WHAT PATIENT IS IN EACH*
Time and day Detail when the activity takes place and if this changes *Workshops – evenings, Fridays?* *Exhibitions - Clinical opening times*
Access Explain the methods used and the means or opportunities available to find and participate in an activity *Workshops – TYA unit space, meeting room, online* *Exhibition – accessible*
Privacy Tell us if the location of the activity is accessible by anyone (including those not engaging) or if it is only open to those who are part of the activity *Workshop - private setting (a private room on a hospital ward where only patients are present)* *Exhibition - a public setting (an art gallery where members of the public are around)*
Additional comments *There were two distinct environments*

What is the atmosphere (character, feeling, or mood) like where the activity takes place?
Comfort Explain the degree to which the setting of the activity elicits a sense of ease, safety, and relaxation *Space that feels comfortable and safe*
Belonging Explain the degree to which the setting and environment elicits a feeling of being included *Feeling welcomed; at home*
Familiarity Explain the degree to which the setting of the activity is known or unknown by participants *Unfamiliar*
Ambiance Describe the mood or tone of the surroundings where the activity takes place *Nurturing*
Organisation Explain how the delivery and management of the activity is perceived by participants *Efficient (with some inefficient) processes, corporate feel with some organic feel*
Additional comments *The atmosphere of the activity – safe??*
PROJECT SET-UP
What economic resources (if any) are connected to the activity and its delivery?
Participant charges Describe any monetary transactions connected to or part of the activity, and if there are any support structures in place to ensure equal distribution of monetary resources *Free, non- compensated (paid to attend). Some artwork was sold.*

Project funding Explain if and how the activity is delivered using monetary resources obtained through external organisations, individuals, trusts, charities, or the government to be used for the purpose of delivering the activity *Grant funded*
Fees Describe if any people involved in the delivery of the activity are paid for their time *Salaries for staff*
Longevity Describe the duration of the activity across time and whether the activity can be upheld and supported with the economic resources available *One-off*
Environmental sustainability Tell us if best use of resources are made in view of what may be harmful to the environment *N/A (individual choices). No waste?*
Additional comments *Complex re economic resources associated with the activity*
What person, people, group(s) and/or company(ies) is/are in charge of organising the management of the activity?
People Describe if there are any people 'behind the scenes' of the participant-facing aspects of the activity *None*
Affiliation Explain if and how the activity is connected to an organisation or institution *None? NHS Research?*
Branding Describe the language, visual imagery, ethos and/or symbols that represent any connected organisations, institutions and/or the activities *NHS Trust named on labelling*
Collaboration Describe any partnerships with other organisations involved in the delivery of the activity *Youth Music*

Patient and Public Involvement Describe if the activity involves actively including participants or the public in the process of designing and organising the activity *Young people's patient and Public Involvement group (PPI (Patient and Public Involvement)), study steering group.*
Additional comments *This was a formal research project*
How do participants find out about or become enrolled into the activity?
Formal referral Explain if there is a referral into the activity from professional services such as via established organisations or schemes *Referral by clinicians*
Informal referral Explain if there is a referral into the activity from personal, social group, or community connections or networks *Through music making project*
Choice Tell us who decides if the participant will enrol in the activity *Participant choice*
Advertising Describe how participants find out about the activity via publicity materials, and whether these materials are targeted for particular groups *Organisational advertising, reaching out to those with specific health conditions,*
Additional comments *This was a formal research project*
Do you signpost or refer to any services, resources, support, or advice beyond the activity itself?
Inter-sector signposting Describe any resources and information provided about other arts or cultural activities that may be suitable for the participant(s), or if participants are directly recruited into such activities *Recommendation from other arts activities*

Health-sector signposting Describe any resources and information provided about healthcare or support for mental or physical health, or if participants are directly recruited into such activities *Signposting to psychological support*
Social signposting Describe any resources and information provided about social support services/activities, or if participants are directly recruited into such activities *Signposting to welfare or caring support*
Other-sector signposting Describe any resources and information provided about other sectors, or direct recruitment into such activities *Signposting to educational opportunities, work placements, or enterprising or business opportunities*
Safeguarding referral Describe if and how action will be taken to protect participants from emotional or physical harm if it is needed *Referring a patient to a counsellor if it becomes apparent that they require such support*
Additional comments *This was a research project*

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