Meaningfully engaged?

Exploring the participatory arts practices of adults with PMLD.

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Knowledge is reliable, safe and certain as long as it is held in mono-logical isolation and synchronic arrest. As soon as it becomes mobilised and communicable, this certainty slips away and truth is negotiated in the gap between self and other, through an unfolding, dialogical exchange.

(Kester 1)

The beginning thus equals the end, and makes an end in itself.

(Nancy 99)
Abstract

Central to this practice-led interdisciplinary research were a group of seven adults with profound and multiple learning disabilities (PMLD). People with PMLD attending day services can face inadequate activities, and this study has proposed that participatory arts can positively complicate and challenge what are often reductive ways of engaging with this community. It has done so via an intervention of visual arts practices in a day services setting and subsequent investigation of what conditions and by which approaches, their utility might constitute meaningful engagement (ME). A definition of ME for adults with PMLD is absent where the disciplines that inform this study intersect and it is proposed here that meaningful activities (MA) can provide concrete examples by which to understand that ME is taking place.

The study was based on an intensive intervention of participatory visual arts workshops over a twenty-week period for which NHS ethical approval was gained. Tools used included GoPro and hand-held cameras, paint, charcoal, clay, paper and plant material. The study generated seven cases based upon qualitative data that examined the arts making processes of its participants, including visual data such as photographs and film stills, and written data including questionnaires, consent and capacity forms and a research journal. These were thematically analysed and thick data narratives developed in relation to the primary research question, for which a combination of the film editing and qualitative data analysis software packages, Premier Pro CC and Atlas.ti were utilised.

This interdisciplinary practice-led study evolved from the field of the participatory arts and was influenced by the literature on inclusive research approaches and direct practice in Learning Disability Studies. Here debates constellate around both including people with PMLD in research and developing their active support. It contributes to the literature by developing a greater understanding of how by evolving inclusive research approaches, incidences and forms of ME could be understood through the lens of participatory visual arts practices. I proposed practical and theoretical frameworks for working towards ME as sets of conditions and principles, and engendered institutional change by taking the lead from the experiences of expert participants and their supporters in the identification of modes of ME. This thesis was developed in an accessible format as a book of photographs for learning disabled audiences.
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Preface

This thesis is comprised of three parts: this written text, an accessible photograph book and a DVD housing 7 films addressing the individual processes of each participant. The films are shown without sound in order to maximise their accessibility and in line with my participatory arts practice in this area.

In order to illuminate the thesis fully, the case studies should be read with their in-text images as reference points. The related process films, which are housed on the inserted DVD, can be watched after reading the case studies.

The photo book is positioned as a place for accessibly communicating and making visible the meaningful engagement of the participants in the study, and the working practices of those supporting them.

The Atlas.ti network views (Appendix G) offer graphical representations of the relationships between different data types. They show the reader the evolving connections between codes and as such can be viewed as presentations of work in progress showing the thinking that was developed during this doctoral study.
Acknowledgements

NHS ethics approval was obtained for this study. The approval letter is at Appendix B. I gratefully acknowledge the financial support of the UK AHRC and the University of Brighton Springboard Grant, my thanks also to the University of Brighton Doctoral Centre (Arts and Humanities). Thank you to my supervisors Professor Alan Tomlinson, Alice Fox and Professor Hamish Fyfe for advocating for a wider spectrum of people and practices in research to be viewed as contributing quality within the academy.

Many thanks to the Journal of Arts and Communities, and to Bloomsbury for supporting the publication of my work during the period of this study. My gratitude to the Winston Churchill Trust for my Travel Fellowship in 2013 – it informed much of the thinking that led me here.

My heartfelt thanks to Josh, Katherine, Hayley, Rob, Sharon, Dani and Charlotte for everything you have taught me. To the wonderful staff at Portsmouth New road Day Centre, families and key supporters who were involved with and encouraged this research.

I have been fortunate enough to have collaborated with some wonderful colleagues whose vision and energy have sustained my practice and broadened my thinking. Thank you to Jo Ball for the invitation that set the ball rolling and for your professional generosity. Dr. Natasha Mayo I have loved all our projects and I look forward to more! Thanks to the Welsh participatory arts community where innovation and quality are pursued in equal measure, and to colleagues further afield who continue to inspire.

Jade French, you are the best professional sidekick a person could ask for and a wonderful friend. I am really excited about the ways in which you are leading the sector in learning disability curatorial practices and am looking forward to bringing our research interests together in future projects.

I owe a debt of gratitude to so friends and family members for stimulating conversations, support, guidance, cake, coffee, art-making, yoga and laughs. You have pushed me on, and I am so glad you did.
Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed

Melaneia Warwick

Dated

17th July 2017
Dedication

This is for my mother Leah, who encouraged all of my journeys.

And for Mick, I could not have achieved this without you.
Chapter 1

Introduction

This doctoral study began with a fortuitous meeting. Following a conference co-presentation to the College of Occupational Therapists, I was approached by Jo Ball, a Senior Occupational Therapist working for the NHS and based in Portsmouth. A brief but heartfelt conversation around my experience of working with adults with profound and multiple learning disabilities (PMLD) led to an invitation to visit New Road Day Services in Portsmouth with a view to possibly locating the data-collection for this doctoral study there. I would ultimately come to work with seven adults with PMLD over a twenty-week period via participatory arts workshops. The group had a range of preferred modes of communication; all but one were wheelchair users and one suffered from quite pronounced ill health during the period of data-collection. All members of the group needed a minimum of 1-1 support to varying degrees but the need for the Day Service to employ occasional agency staff meant that this support was not always from the same person or people.

The aim of this practice-led study, which is funded by the AHRC, is to assess how adults with PMLD can inform the meaningful engagement agenda through their attendance at participatory arts workshops. It developed an innovative methodological mix that included inclusive and participatory action research (PAR) methods and combined participatory video and art-making techniques. Tools used included GoPro and hand-held cameras, paint, charcoal, clay and plant material. The methodology included 7 sustained qualitative case studies each with a rich database; these presented illustrative and expanded instances of participants’ developing processes developed through thick analysis (Denzin 33; Ponterotto 540). Although emerging from a participatory arts practice, this study aspired to a broad disciplinary reach. Indeed in the lifecycle of the project, its developing theory was peer-reviewed by research ethics, participatory art and education audiences (Appendices A, B, E and F).

The PMLD Network has described people with PMLD as having “more than one disability, the most significant of which is a profound learning disability…and additional sensory or physical disabilities, health and mental difficulties and difficulty in communicating” (PMLD Network). They note that most people will need high level of support people in their daily
lives. Lacey and Ouvry have highlighted the additional needs that can exist alongside a person’s learning disability, “autism, sensory impairments, physical disabilities and a whole range of condition and syndromes” (1). They also note that people will have, “significant weakness in learning abilities, communication, personal and social skills and/or sensory and physical development (1). The working definition of PMLD within this study was: people with PMLD have more than one disability, have profound learning difficulties, have difficulties communicating, may have additional sensory impairments and complex health needs, and need high levels of support. Additionally this working definition acknowledges that as a group, people with PMLD are not homogenous in their needs, preferences or communication styles; a discussion on the positioning of participants involved in this study in relation to the definition of PMLD is undertaken on page 16.

This introduction presents the context for this research and is followed by a discussion on terminology and the research question in order to locate its distinct standpoint. The thesis proceeds with an introduction to the seven case studies that have, through their interactions with myself, key supporters, and the visual arts materials explored in the study, shaped its thinking. A case is then made for the use of the arts in the study; the cases too provide the context for a discussion on the entangled ethics that I had to navigate in order to conduct research with this constituency in the UK, and about the approaches taken to unravel these. Examinations of the disability and intellectually disabled arts literature with further specific discussion of the PMLD population are undertaken and this illuminates the need for a definition of ME to be present in the literature. This is followed by explorations of inclusive research practices where these influence the study, and the role of participatory video. The thesis next presents its methods and research design via an interdisciplinary literature review that looks at inclusive research and the use of creative methods before discussing the PAR method in the context of this study. It discusses the opportunities and challenges of the design for this study before progressing to a reflective chapter outlining my experiences of the NHS ethics approval process. The thesis next looks at the data analysis and collection strategy used for the study and offers a critique of these and a discussion of the tools used to undertake them. The last main section of the thesis is the analysis of the cases with discussion on how this was governed, individual case analysis and a drawing together of the understanding of ME gained through the cases. The conclusion makes methodological recommendations and considers how this research might be applied to the wider literature.
**Terminology**

Given the interdisciplinary nature of this study it was important to look at the terminology in both the participatory arts and relevant inclusive research practices in order to formulate useful definitions. A good many nominations have been given to the practice of professional artists working with untrained others and this is in part because the practices occur across a spectrum of models. Terminology for naming this set of practices includes: inclusive, community, dialogic, relational, and collaborative arts, or more simply. "Artists who wish to engage with people" (Salamon 5). During the writing of the sector underwent closer definition resulting in the term inclusive arts becoming specifically aligned to collaborative making between professional artists and people with learning disabilities (Fox and Macpherson 2). Although this study is closely informed by inclusive research practices, it does not utilise the term ‘inclusive’ to describe its approaches to its arts engagement; it considers these as creative-enabling rather then collaborative. Further discussion is found under *Positioning the Researcher*.

The term participatory arts is commonly used and has an established place with commissioners and funders, on the ground organisations and University Research Centres. The term inclusive research was also contemporaneously reviewed in the light of "dramatic changes" (Nind "Inclusive Research"viii) to the practices under its umbrella, which include participatory, emancipatory and action research. This study had an interest in democratising the research process and it is *here* that collaborative focus was relevant and found its place in the study. The learning from this research was directed towards a series of recommendations that contributed to the improvement of the practice both at institutions such as day services, and more broadly with a reach into studios. This was a doctoral study in the participatory arts then whose collaborative focus was found in its inclusive research processes rather than in its art-making approach.

**Research Question**

This research aims to add to the interdisciplinary literature base by building on emerging discussions on inclusive research practices, making recommendations for the development of participatory arts practices with PMLD populations and contributing to the debates on ethical approval for creative methodologies.
Central to these aims is the research question:

RQ: How can adults with profound and multiple learning disabilities (PMLD) taking part in participatory arts workshops inform an understanding of meaningful engagement in this context?

A number of objectives were identified to support the investigation of the research question:

RO1: To identify the ways in which adults with PMLD engage with participatory arts workshops.

RO2: To identify what is perceived to be meaningful about this engagement.

RO3: To explore the ways in which care staff support meaningful engagement in the participatory arts setting.

RO4: To contribute to the understanding of the specific principles and conditions that are commonly utilised and developed in order to facilitate participatory arts workshops with people with PMLD.

RO5: To devise 7 Process Films that present new ways of working meaningfully with adults with PMLD.

RO6: To contribute the development of the meaningful engagement agenda through the dissemination of a series of recommendations highlighting best practice.

Participants

This section of the thesis introduces the adults who participated in the study from the perspective of their assent and dissent positions and what was collectively known about their creative experiences and sensory preferences. The former are the behaviours that people use to articulate particular messages and positions such as likes, dislikes, points on the emotional spectrum and a desire to stay or leave the room. The approach taken for establishing participants’ conditions was to avoid a medical or diagnostic position but rather to establish an ability-focused stance. I did not consult medical records in order to work this out; rather a pen picture was collaboratively developed through the capacity
assessment and consent processes. It was clear that participants presented on a spectrum against the working definition of PMLD given above. It was also evident that some aspects of their participation were previously untested and presented potential barriers to fuller expressions of engagement. The social aspect of the workshops, interactions with new creative materials, and episodes of ill health exasperated difficulties in communicating for some. Taken together with the pen pictures, there emerged a range of different abilities such as physical capacity, which included wheelchair users and non-users. Support needs ranged from 2-1 to 1-1 and communication facilities extended across people using a small range of sounds to those likely to use repetitive words. Other participants used verbal communication limited to partial sentences; some were able to engage in short conversations. Sensory impairments were also varied and the use of music had to be carefully negotiated around table arrangements in order to meet the needs of those who really enjoyed the radio, and those who could not tolerate loud noises. In addition the use of touch differed from participants who enjoyed physical interactions to those who found touch or even close proximity, stressful and unwanted. Where participants had taken part in art-making previously, the nature of activities was not always clear, although discussions with staff and parents revealed that participatory approaches proposed for the study would be new. These positions were established through the ethical approval processes for the study and included opinion from NHS, day services and residential staff and parents. All of these opinions contributed to a picture of rolling consent, as well as providing myself and staff with a baseline from which to work as sensitively as possible with participants. These baselines were revisited in the workshops in order to establish rolling consent as a point from which to investigate the research question, and begin to understand what might constitute ME for participants.

Josh

When the study was conducted Josh was 23 years old and living at home; he had a recorded enjoyment of participating in sensory activity relating to sound and texture. It was clear to his family and care staff that Josh would be very stimulated by and enjoy playful physical contact and the opportunity to create and interact with loud noises whether heard discretely in his left and right ears or in stereo. Josh was able to differentiate changes in light and dark and enjoyed tactile explorations; his open, inquisitive character and close friendship with Hayley who was also participating in the study, was commonly understood
in the day centre. To express his interest in an object or person Josh would use smiles, laughter, direct his focus at and raise a hand towards an interesting sound. These signals would also be used to indicate 'yes' and 'ok'. If Josh did not want to continue or wanted to say 'no' he would turn down his mouth, throw objects away or turn his head down and away. In the case of not understanding something, Josh would give no response.

**Charlotte**

At the time of data-collection Charlotte was 28 years old and living in a residential home; she had a recorded enjoyment of participating in simple arts activities such as card making. However, further details about this such as what materials and tools Charlotte liked to work with were unavailable during the time that the workshops were being run. In a conversation I had with Charlotte’s father after the data-collection period, I learned that she had enjoyed painting from a very young age when a brush had been tied to her hand in order to support her to hold it. Charlotte's bubbly extroversion and frequent laughter were well-understood character traits and a consistent message was how much she loved social situations. In order to express her enjoyment she would look, laugh and smile and in addition to these signals Charlotte indicated 'yes' through eye contact and by raising one of her arms. Charlotte had a consistent language for expressing her needs and interests, most clearly by moving towards and looking at objects and by raising one of her arms combined with very focussed attention. In order to express 'no' or 'stop' Charlotte used a neutral response.

**Sharon**

At the time of the study Sharon was 50 years old and living at home, her mother had thought that she would enjoy taking part in the art sessions, highlighting the physical benefits it might bring her to be using her hands in new ways. Sharon had participated in some watercolour painting sessions although it was not clear how frequently she had attended, or for how long. I did learn was that Sharon did not like to touch or hold new objects although she did enjoy some sounds such as the twinkling of small bells. Sharon preferred to get to know people over a sustained period of time and would gain confidence in them slowly; once a relationship had been established she would smile, laugh and use eye contact and a directed gaze to indicate 'yes' or 'ok'. In order to express 'no' or 'stop'
Sharon would move away from a person or if an object, most likely drop it. In order to communicate that she did not understand Sharon put her fist to her nose and used a worried expression, or in some cases chose not to respond at all. Sometimes Sharon would choose to use spoken words including 'yes', though this was not consistent and so account of language and non-verbal communication taken together was important to developing a reliable picture of what she wanted to communicate. For example when her support worker had asked if she wanted to 'do some painting' Sharon had laughed, smiled, and used eye contact to say yes.

**Dani**

When Dani joined the study she was 25 years old and living in a residential care home. She had a recorded enjoyment of participating in arts and crafts activities and could reliably and consistently express this though talk and gestures such as nodding her head. Previously Dani had enjoyed delicate watercolour painting with a brush and beading using Fimo clay, as well as creative activities such as cooking and baking. However, Dani found it challenging to attend any of these sessions regularly and had always chosen to leave courses after a few sessions. Even though Dani had consented to attend the full 20-week data-collection period, an early departure was flagged up as a highly possible outcome of her participation. To support her to stay in the room, careful attention was given to her dissent positions, which were to withdraw, go quiet and take herself away or seek out particular members of staff and say that she was feeling unwell. Dani had a good deal of manual dexterity and it was collectively understood that she was very independent. This latter point meant that her support staff would need to be present whilst maintaining a distance when Dani was working on her artwork, but to note when she might need support and encouragement.

**Rob**

Rob was 21 years old and living at home when he took part in the study. He had been attending 1-1 sessions at the Day Centre and it was collectively understood that he was a quiet person who had a gentle character. Rob had, in the past, enjoyed arts activities and had found them stimulating, although the detail of these was unavailable. Rob expressed his 'yes' and 'interested' positions through direct eye contact, putting his head up and
tracking objects and people. Conversely if Rob wanted to express 'no' or 'not interested' positions he would push away, move away or put his head down; if he did not know or understand Rob would take a neutral position. Rob's mother had informed me during the consent process that he would respond well to an upbeat tone of voice and positive energy, and that he liked touch as a reinforcer to communication. It was known that Rob had been suffering from bouts of ill health towards the start of the project but full consent was gained for his attendance at all 20 data-collection sessions. It was important to day centre staff who worked with Rob that he be supported to attend on the sessions that he was able to in order to expand his opportunities to try a new activity.

**Hayley**

Hayley was 23 years old and living at home at the time that the data-collection took place, her mother reported that she had a strong character and enjoyed being in control of situations. Hayley had a very close friendship with Josh and frequently advocated for him by telling staff what she thought Josh wanted and needed. Day centre staff informed me that Hayley enjoyed jewellery making and her mum had said how much she thought Hayley would enjoy participating in the project. In particular she noted that Hayley would enjoy being able to watch herself through the filming that was planned for the study, and that she would express enjoyment and 'yes' through laughter, smiles and by staying, looking, engaging and reaching. If Hayley was unhappy or wanted to say 'no' she would stamp her feet, shout, leave the room or back away. She would need time to digest a question, perhaps with a break and then repetition but if she was unsure of the answer she would use non-verbal gestures, in particular raising her arm. Other than this Hayley would change the subject.

**Katherine**

At the time of the study Katherine was 23 years old and living at home. Day centre staff had thought that she might enjoy activities that included references to the cartoon characters Super Ted and Spotty. Staff shared with me that Katherine enjoyed colouring in images of these characters with felts and colouring pencils; they reported that they had been working successfully with her in this way in terms of her remaining engaged and relaxed. Katherine had previously struggled to work on a shared table, finding it stressful to
be too close to other participants and articulating this by shouting loudly to indicate that she wanted to stop or was unhappy. I was informed she could work on her own table in a shared space as long as her single support person could reassure her when the environment became noisy or unwanted people were to approach her. When Katherine wanted to say ‘yes’ or ‘ok’ she would use spoken words and was able to do this consistently and reliably as she had a very good working memory. Staff had reported that Katherine would not want to touch the paint material with her hands or to get any of it on her clothes; it was suggested that she would not be comfortable with getting it onto her paint shirt either. Lastly Katherine would be confident in building up a picture of association with people and items, skills learned and activities.

**Positioning the Cases**

Ragin and Becker describe cases as those that “typically invoke additional units in the presentation of their research” (2); the participants involved in this practice-led study were placed at its heart with emphasis on them as individuals. This was in part necessitated by the ethical approval and related recruitment processes which required assessments of capacity and expression of consent to be made with individuals. A focus on situated ethics to ensure participants’ in-the-moment assent and dissent positions were respected also reinforced this position. Resulting understanding of ME were subsequently shaped at the level of the individual and in part answered the question “what is this a case of?” (Ragin and Becker 6. My emphasis). In this way cases were developed to reflect the language of the individual and their experience. Only when ME had been understood within the individual cases were patterns and consistencies across all cases identified. The choice to look across the cases was taken in order to draw out practical working approaches and principles; the Overarching Case Studies chapter reframes the question ‘what is this a case of?’ by taking an overview of all the cases.

**What Art?**

This study is located at the ‘inventive’ end of the Audience Participation Spectrum (James Irvine Foundation 5) wherein creative control is given over to participants who ultimately shape the artistic experience. Interests that extend out and away from traditional object-oriented outcomes and audience participation in singularly defined gallery moments such
as exhibitions have shaped what is defined as art here. This participatory practice-led study was not a critique of the institutional setting in which it took place; it did not attempt to interrogate existing structures and processes. Rather it took the familiarisation of and sensitisation to these as a focal point, a place to locate the perimeter of what would be thought of as art therein. Art then, was constructed as a reflexive, socially engaged practice rather than a spectator dynamic that asked an audience to simply 'receive' the outcomes of the artist’s work.

Through its analysis of the ME context the study identified characteristics that made a potent contribution to the success or otherwise of Meaningful Activity (MA) via supporting conditions or barriers. Given its complex nature, enquiry in this area would not be able to fully reveal the human and creative nuances that contributed to success, failure or unexpected outcomes of the practice. It was not easily slotted into pre-defined shapes and took the road less travelled, indeed it was an intentional attempt to establish new relationships between artistic production and the development of working practices in the care sector as well as being aligned to a paradigm shift in contemporary art (The One and the Many 22; Belfiore and Bennett 16). Indeed, a characteristic of this study's exploratory nature is that the report at its heart "Valuing People Now" (Department of Health 24) in lieu of being subjected to the same evidence-based emphases as established policy relies instead, on word of mouth from family members and those working in the care system. Although the weight and importance of these user-led opinions is not under debate here, in the arts a lack of suitable robust evaluative frameworks (Blanche 8) has resulted in a diminished focus on the outcomes of the intrinsic value of participants’ artistic practice. Whilst in the arts more broadly significant weight is given to aesthetic condition as a quality outcome of an art-making endeavour, this should not preclude an aesthetic diversity, particularly one that tests the status quo (Artforum.com). Rather than limitation, this distinction is one that is “literally vital” (Matarasso 8) offering a mixed bag of meaning-making opportunity, recognising that the arts are "hardly crystallized and fixed" (Belfiore and Bennett 16).

While it is clear that no single model for the participatory arts exists, the literature lays out an existing range of possibilities that extend their foci of process and production along a scale that includes professional artists as creative director to untrained participant as sole maker. Extending creative opportunities broadly across society, and in particular where
creative projects are offered as a salve for societal ills (Belfiore and Bennett, 8), does not necessarily equate to the intrumentalisation of the arts. Instead writers argue for the breadth of the creative offer as mirror to the cultural evolution of place. Kester outlines the direction that the literature is taking in terms of understanding this work:

We are less concerned here with what has become a largely sterile set of debates about the status of this work as “art, ”… this doesn’t mean we aren’t concerned with the artistic status of this work, only that we believe a deeper understanding of this status is unlikely to result from the crude opposition between ethics and aesthetics or singular and collective authorship that has characterized recent critical dialogue. Rather, it requires a sustained and immersive engagement with site, process and practice that is able to move fluidly from the power dynamics encoded in the physical proximity of individual bodies to the macro-political framing of local or situational gestures in the context of global neo-liberalism (The one and the many 1).

Key to detailing the breadth of participatory arts activity has been the Participation Spectrum (James Irvine Foundation, 2011) and as indicated, this research project sits firmly towards the end of the spectrum where participant is sole maker of the work. The existence of such a model however, does not determine or even indicate a ‘best’ art form or model of engagement for leveraging social change from projects in this sector. Rather the focus echoes the importance assigned to the alliance between artists, participants and significant others, “relationships…between intention and means…between art and society” (Matarasso 2).

It is clear that art practices cannot always be pinned down; indeed they may remain elusive, “beyond the control…of artists themselves” (Matarasso 8). Some writers position this characteristic as positive, inextricably linked to the act of creativity and an indicator that arts practices will flourish and art will retain its own truth wherever it is used (Kuppers 14; Matarraso 56). Yet conventional art criticism lacks the critical structure to effectively debate participatory practices whilst allowing for their particular complexities. Discussion of artistic practices has relied heavily on what Kester has called "monological thinking" (The Device 3) which can be described as a critical ivory tower constructed of a series of collaged theoretical positions pre-ordained as acceptable. Whilst the usefulness of these
established critical practices is unambiguous in some contexts, it is evident that they do not serve the wave of newer participatory practices. A broadly acknowledged view of acceptable art as constructed by high-status cultural institutions is slowly changing as relativist and relational expressions of the arts have taken centre-stage in the mainstream. This movement has created a niche market for a rejection of traditional modes of critique, embracing an authentic, bold directness. Testament to the increasing centrality of these positions was the inclusion of The Encyclopaedic Palace at the 55th Venice Biennale where curator Gioni called for a celebration of the “illustrious nobody” (Labeinnale).

Kester reminds us to view relational and socially engaged arts practices on “continuum that includes biennial-circuit stalwarts like Rirkrit Tiravanija, Thomas Hirschhorn and Santiago Sierra to that of more overly activist but less visible groups such as Ala Plastica…and Platform” (“Response to Claire Bishop” 1). The Hayward Gallery’s ‘An Alternative Guide to the Universe’ (Southbank) and the Wellcome Trust’s ‘Souzou’ (Wellcome Trust) contributed to the growing momentum. Elsewhere in the mainstream socially engaged arts have been positively received: Martens’ Artis Mundi 6 nomination reflected a political and social agenda. Critically, Martens was self-reflexive about the nature of projects that included vulnerable people, admitting to the artist's “dependencies on global inequalities” (artesmundi.org). Yet Martens’ response to this stark reality is to centralise the role of a reciprocal artist / participant relationship that extends beyond the creation of simple concrete objects and encompasses knowledge and expertise that can be shared where the direction of travel is from participant to the wider community. In the UK the grassroots What Next? UK wide catalyst movement stands for an increased access to the arts stating that:

The arts and culture enhance every aspect of our lives: the vibrancy of our cities, the identity of our rural communities, the future prospects of our children, the quality of our democracy, the sustainability of our environment, the employability of our workforce, our ability to make sense of our own experience and to empathise with others (Whatnextculture.co.uk)

It is not a new idea that art can be a powerful force that gives voice to marginalised groups and that they have a “humanising power” (Belfiore and Bennett 176). Yet this view in isolation risks positioning the arts as an instrument; rather than Bennett’s
"governmentalisation of social relations" (151), which sees populations as recipients of a ruling political agenda; there are opportunities for communities to impact their experiences onto political thinking. Kester suggests that one of the ways this can be achieved is through the critical tools used to discuss artistic works being embedded in participating communities who could better convey unique, localised perspectives and speak to enduring historical and contemporary connections to arts and politics. What supports these tools to develop is the artists’ understanding of their own motivations, their ‘why’ contributes to the sense of scale and scope of the project.

Within this study, participatory arts are framed as an “unfolding practice” (Kester The one and the many 1) that forefront their sequential nature and welcome uncertain outcomes. I followed Kester’s emphasis for focus on continuous engagement with site, process and practice so that whilst the study was necessarily designed around a practical and ethical framework, the creative direction that participants took within workshops was led by them. This approach was beneficial for a PMLD constituency as it viewed the evolution of practices across an extended period of time, disrupting institutionalised perceptions of development and success by enabling care staff and key supporters to notice these differently.

**Entangled Ethics**

Within the context of this study I was institutionally required and professionally compelled to attempt to address some of the problems and difficulties that could come about from developing socially engaged arts practice with people who might lack the capacity to consent to participate. These interests were addressed through the unravelling of the project’s 'entangled ethics' which are defined as complex, often dependent ethical moves required throughout the study and occurring in varying knots of intensity as it progressed. These moves were complex in that they involved a number of stakeholders with professional, familial and institutional perspectives on, and relationships with, the study participants. In order for these ethical unravellings to take place, it was important for me to reflexively hear the comments, concerns and expertise of day centre staff and managers. These were facilitated within a framework of ongoing reciprocal knowledge exchange whilst ethical approval was achieved through meeting both the University and the NHS Research Ethics Committee (REC) governance requirements. Additionally family members
and residential care home staff were consulted and communication maintained with key people throughout the lifecycle of the project.

The process for resolving the entangled ethics for this project began in its third month with preparations for the NHS Integrated Research Application Systems (IRAS) online application (Appendix B) and subsequent Research Ethics Committee (REC) panel interview. Planning for this took part alongside completion of the University's own ethical approval process, which created additional administrative and time burdens on the study. The IRAS application was conceptually involved, time-intensive and required a rigorous fore-fronted approach to project planning that was in places methodologically at odds with the iterative reflection-action cycles of participatory action research. The latter was evident in particular in the wording of section A13 of the IRAS form which stated "it should be clear exactly what will happen to the research participant, how many times and in what order" (myresearchproject.org.uk). The final application was 15,000 words and included fully conceived appendices for participant information sheets and consent forms, including versions for Best Interest consent. My reflections on this process are discussed in the intertextual reflexive essay in Chapter 4.

The day centre provided the location for the next series of ethical knots to be untangled through an equitable sharing of practice and knowledge with Centre staff and via a robust procedure developed to recruit participants to the study. In order to share my previous practice, support the initial development of trust, and emphasise my interest in mutual learning, I planned a 'Reciprocal Sharing Day' attended by centre staff and managers. This enabled attendees to gain a sense of the project, ask questions and share their expertise and ideas without feeling coerced into taking part. Later the notion of shared expertise would be reinforced by a series of data-analysis sessions with centre staff that enabled them to view and comment on short pieces of video collected during the workshops. There was a clearly defined and NHS approved two stage process for the recruitment of participants, a series of interviews that established whether a person had capacity to consent to participate followed by the obtaining of consent or best interest consent. These were complex events involving centre staff and managers, a senior NHS occupational therapist, parents or key supporters, and myself. Key considerations for the capacity to consent interviews were the management of the space where the meetings took place such as the arrangement of furniture, the use of lighting as well as the inclusion of
appropriate objects of reference such as paintbrushes and a film I had previously made about my work with a PMLD group in Wales.

For the best interest meetings I brought the same short film and photographs and showed examples of artworks made in the previous project. These inclusive approaches were reflected later in the workshop open door policy to family members and key supporters, the coffee morning that took place halfway through the project and the showcasing of participants’ work to other day centre users. In their focus on access, transparency, respect and consistency these strategies added depth to the overall ethical approach taken and were well received by centre staff and other key supporters. The thread that ran through all of these activities was an attempt to understand and then describe what users of the project felt was meaningful to them. This was supported by a methodology that could assimilate visual arts practices with inclusive research strategies. What characterised these arts practices was their relational nature and the development of new modes of reception by creative-enablers that had particular awareness of the parameters of agency and affect.
Chapter 2

Literature Review and Methodology

This is an interdisciplinary study that intersects participatory arts practices, inclusive research practices in education and learning disability studies, and debates on situated ethics in particular where these intersect PMLD populations. It identifies a gap in the literature for a transparent methodology with practical application to on-the-ground projects, the combination of which have the potential to develop existing practice in the sector. I reject constructivist and quantitative research methodologies because of their individualistic positioning of the research participant. The understanding of the term 'individualistic' here is informed by the work of Simmons and Watson who define it as an understanding of people with PMLD gained “in abstraction from the everyday situations and relationships that they live through” (51).

Inclusive research is aligned to participatory arts practices in its change-making concerns. Participatory practices exist on a sliding scale of audience participation and may not always be politically radical in their aims to challenge power hierarchies; they could be utilised to bolster prevailing practices (Schostak and Schostak 45). Inclusive research is often conducted in the workplace or similar places where participants congregate, and is based on ongoing action and reflection cycles. It is often interpretive in its approach (Wisker, 2008) and where the focus is to question the established order, inclusive practitioners remind others in the sector to be aware that the "dominant views will require some form of narrative deconstruction....an unchaining of the sequences of action 'glued' by the key rigid designators" (Schostak and Schostak 60).

Examining Disability Arts and Intellectual Disability Arts

The development of the Disability Arts movement can be mapped across the last forty years starting with the establishment of the disability arts organisation Shape in 1976 (Sutherland, 7), yet it is “an evolving concept and at any given time there has not been a unity of approach” (4). Within the output that is included in this broadly termed movement, creative acts are often concerned with or informed by the experience of disability; some such acts have reached the mainstream. Across a broad spectrum of genres are high
profile works such as Tony Heaton’s sculpture ‘Great Britain from a Wheelchair’ (disabilityartsonline.org) and ‘Survival of the Shittest’ a rap album by disabled artist Mat Fraser (disabilityartsonline.org). Works such as these helped to develop thinking related to the Social Model of disability and alongside Equalities Act (2010), supported people to articulate the limitations they faced in terms of access to wider society. In conversation with these positions, contemporary disability arts literature is constructed through a sociopolitical lens (Goodley and Moore ix; Shakespeare 214; Davis 1) and through this a critique is made of the barriers that limit and exclude people from participating in, and creating, cultural events. Post-DDA work includes, for example ‘The Way Ahead’ by Caroline Cardus (disabilityartsonline.org), which portrayed the everyday inequalities the artist encountered whilst using her wheelchair.

Galton’s legacy of bringing into society, via the content of his statistical theory “the concept of a norm, particularly a normal body, and thus in effect (creating) the concept of the disabled body” (Davis 3) still pervades. The absolute person is an aggregation of ideal traits that forces the Other to become a point of comparison to this ‘ideal’ (Said 332). That these traits are largely unattainable further deprecates the disabled person, forming a “dominating, hegemonic version of what the human body should be” (Davis 5). The effects of this can be seen in the writing of Johnson: “it’s not that I’m ugly. It’s more that most people don’t know how to look at me. The sight of me is routinely discombobulating” (Davis 508) and Fries: “can only one of us be beautiful? Is this your plan?” (Davis 528). Arts participation literature however, clusters around the view that participation can be a positive experience for people with disabilities (Atkinson and Williams 13; Heathcote, 118; Fox and Macpherson 2), not only in and of itself but also for its important political and self-advocacy bent, anchored in the premise that “to have a disability…is to be part of the Other ” (Davis 8). Lapper, in discussion of her public sculpture ‘Alison Lapper Pregnant’ reflects this view, “the sculpture makes the ultimate statement about disability - that it can be as beautiful and valid a form of being as any other” (Millett-Gallant 398).

People with learning disabilities have been excluded from the Disability Arts scene. Their use of non-disabled supporters has not been a fit for a model that has emphasised a hard won fight for independence. “The disability arts movement…had to struggle to free itself from the domination of able-bodied professionals” (Oliver and Barnes 104). Where people with learning disabilities have been included in the arts they have found themselves
positioned as Outsider Artists, defined as “without influence from the modern world” (Maizels 1). The work of these artists was discovered in institutions such as psychiatric hospitals and care homes. Whilst the location of this work as ‘firmly on the fringes’ has begun to see a ground shift through its inclusion in mainstream exhibitions (labeinnale.org and artists are not as “culturally isolated” (Maizels 1), it remains a problematic category that refers not to an artistic traditions but as Rhodes has said, to “sociological and psychological factors...about the artist’s fundamental difference to...a supposedly different cultural norm” (qtd. in Maizels 14). Yet it also represents a growth market with superstar artists and sales that have started to match the costs of mainstream work (Creativegrowth.org; incurve.jp).

*Positioning the Researcher*

The status of populations, whose cognitive capabilities are compromised when embarking on creative activities, has been called into question by the prevailing social hegemony which projects on to them an “ambiguous personhood” (Nash, Munford and O Donohue 192) yet it is untrue that “a life without a certain kind of consciousness lacks value” (Fox 793). For a person with PMLD access to what might broadly be called ‘leisure’ activities have often come second to domestic and care concerns (Vlaskamp and Nakken 100). Contributing to or engaging with artistic experiences is complicated by the roles care staff might play in the development of this; the nature of the ‘enabling’ role supporters could take in order to facilitate access risks muddying the waters around authenticity, independence and ownership. This role is not a straightforward one and may involve a spectrum of possibilities; designations proposed in the literature include mediator, facilitator, healer, collaborator, planner, access provider and artistic director (Fox and Macpherson 81; Lowe 25). In its report on practice in the UK sector, Artworks captured over 23 terms for this role (Lowe 25). In their discussion of learning disabled performers Goodley and Moore (53) posited the terms *director, facilitator and follower*. As *director* the arts practitioner takes a meta view on the management of the group and as *follower* she relinquishes influence, “letting go in the sense of following” (Goodley and Moore 53). Another term, 'enabler', is used by Entelechy Arts in the PMLD performance sector where the facilitator is responsible for "stimulating creative activity" (Nash, Munford and O Donohue 190). These designations can be viewed across a spectrum with more or less attention given to the trained artist and participant/s involved in driving the artistic outcome,
be that in the form of process or product. Also implicit here also is the nature of the relationship between these parties; these relationships matter where, “artistic activity, for its part, strives to achieve modest connections, open up (one or two) obstructed passages, and connect levels of reality kept apart from one another” (Bourriaud 8).

This study operationalises the term ‘creative-enabler’ which positions the researcher, carer or key supporter as one who stimulates artistic activity by developing conditions and utilising key principles for it to meaningfully occur, but does not try to control its direction of travel. This position takes the artistic outcome away from being central to the narrative of the work, placing the creative-enabler next to the participant in a helping capacity. The nomination also creates a space for carers outside of the often “hard labour” (Nash, Munford and O Donohue 191) associated with the physical demands of supporting a person with PMLD. The golden threads in this ME are the relationships that are developed, that it is participant-led and social, as Bourriaud has emphasised: “the liveliest factor that is played out on the chessboard of art has to do with interactive, user-friendly and relational concepts” (8). The participatory arts challenge the limiting binaries presented by a conservative, mainstream arts contingent that has previously decided who gets to be called artist and what can be called art.

Flaws notwithstanding, the Outsider Art movement stands as testament to the increasingly porous boundaries and conceptual flexibility of the contemporary arts arena which is increasingly prepared to forego the imperative for its artists to have an association with the canon or the audience. Here “the validity and power of (the artists’) creations are undeniable” (Ice viii) despite them occurring “around the edges of blurred borders” (Ice viii). Traditional caricatures then, strain under the weight of a more interesting possibility for creative expression and cultural contribution that imagines all as candidates, whether or not they engage in the conceptualising that might be preferred by those with by a particular set of cognitive abilities. Taken together, these views cast shade onto projected limitations of the arts to function beyond the traditional studio or performance space. In this conceiving of a less verdant landscape in which artistic endeavor can flourish, they echo Said’s description of the Orientalist mindset that “people over there (are) not like us and (don’t) appreciate our values” (Said xv).
As with Outsider Artists, a person with PMLD may not be perceived as a serious partaker in creative activities; they may be viewed as being “outside of culture,” and what they make as being ‘not legitimate art’ (Nash, Munford and O Donohue 192). This discussion of the performance arts is useful in outlining these reductive binaries of artist/not artist and art/not art, and is appropriated for this study with the purpose of developing the scaffolding of its conceptual framework. Nash, Munford and O Donohue outline a critical difference between the imposition versus the reflexive generation of the performance’s ‘frame’. In the two-man performance Dialog Curios George, learning-disabled actor Knowles was simply “situated and displayed” (192) via an ‘imposed frame’ that would promote a perceived incompetence by the audience members. The lack of a reflexive frame constructed the performance more as a zoo than as a theatre piece: Knowles was peered at as a curiosity. As a non-disabled creative-enabler I performed a reflexive self-enquiry questioning both my reasons for the participatory engagement, and my wider intentions for it. This was viewed through the ethics approval process, supported by a data-collection and analysis strategy rehearsed in peer-reviewed publications and viewed against the conversations and reflections of key supporters, including care staff. Although this study recognises that people with PMLD may lack the capacity to choose the label ‘artist’, it attempts to widen the field of discussion by making a case for them to use it if they and their supporters wish, and to contribute to the cultural lives of their communities via the output of ‘art’. Its reflexive frame conceptualises a space where the PMLD artist’s emerging process is the creative path that leads the team of creative-enablers.

Celebratory Narratives

In addition to a cultural contribution, the literature identifies opportunities for creative work with people with PMLD to positively impact on services that provide their care (Project Artworks 15). This emphasis on both arts and services places such work “in the context of society and social organisations” (Oliver and Barnes 31). There is mutuality here as the arts have, in turn, a role and responsibility to the production and dissemination of images of people with PMLD. If personal tragedy is used as a lens with which to view a disabled person, an inadequate response in the form of a celebratory narrative may be given (Oliver and Barnes 15; Goodley “Learning Difficulties” 161). This is what can pass as evaluation of
participatory arts projects (Bishop “Artificial Hells” 7). Although no doubt well meaning, such simplistic conversations can only convey little of the complexity of the work. Informed and balanced visual images such as those produced by Project Artworks’ Art in Transition project (94) can provide a valuable route towards self-advocacy and improved awareness of the contributions and life journeys of people with PMLD.

To position the arts of people with learning difficulties within the participatory arts sector embraces “untrained” beginnings and in doing so emphasises inclusion (Goodley and Moore 24). It enables sensory routes to privilege artistic process over product thereby enabling an authentic contribution to the arts to be made. It also opens up conversations with PMLD constituencies about labels like ‘artist’, ‘art’ and ‘inclusion’ and in doing so ensures that they can describe their own preferences. The participatory arts also provide useful models for sharing practices in way that do not privilege spoken language through the creation of film and photographic messages. This study utilises these through its creation of process film and an accessible photo thesis in order to air the work, making it available for scrutiny to learning disabled audiences (Walmsley 205).

**The PMLD Population**

*Definitions and the Policy Context*

People with PMLD are among the most disadvantaged in contemporary societies as they are the “excluded among the excluded” (edf-feph.org) often invisible and carry a high risk of being marginalised from their communities. They are extremely vulnerable and often have limited friendships with people outside their familial and care groups. Previous studies with this group highlight the length of time needed to get to know people and to understand their communication styles (Nind “Inclusive research: where does it leave” 23). This latter consideration necessitates close working relationships and subsequently presents a potentially emotive scenario for both researcher and participant once the research ends; such aspects need to be carefully planned and managed. Very little data on this group exists illuminating the segregation that they continue to face (Mencap.org.uk; Choiceforum.org). Indeed during her 2010 Conference presentation, Boxall noted “few studies have sought to elicit the perspectives of people with profound and multiple learning disabilities” and where they have done so they are focussed on, "only a limited number of
behaviours" (Simmons and Watson xiii) rather than on what can be learned from the "relational forms of knowing" in their lives, for example in terms of familial and environmental factors (Simmons and Watson 51). What is known about people with PMLD is that they are a growing population expected to number 22,000 in England by 2026 (the population numbered 16,000 in 2010), and despite some perceptions that they are "not fully human" (Mansell 7), people participate in and enjoy activities, form relationships and can often learn to "use equipment to express at least one important message" (Mansell 8). A major challenge to people with PMLD is the number of separate agencies with which they come into contact, many of whom do not speak to each other and therefore present a disconnected provision of services meaning that families are often obliged to repeat information to each agency separately (Mencap.org.uk).

There has been a “broadening of attention” (Felce and Perry 1) to the lives of people with learning disabilities and this is aligned to a recent social policy shift in the perceptions about, and aspirations for, people with PMLD (Mansell 3). This new focus opens the debate on the challenges and opportunities of including this group in academic research and the implications that arise from doing so (Nind “Inclusive research: where does it leave” 23). Central to the emerging literature is an emphasis on the specific needs of people with PMLD, and the challenges of developing "innovative, creative approaches" to research methodology (Boxall 8). Recent focus in public policy relating to people with PMLD includes opportunities for people to control their lives to a fuller extent and gain momentum from concepts in the 1980s of normalisation and social role valorisation (Simpson and Price 180; Valuing People 14). Much of this shift was driven by the deinstitutionalisation of people within mental health services, and subsequent attempts at their social inclusion (Mansell “Raising Our Sights” 20). Another aligned factor has been the emergence of person-centred planning that encouraged the more active involvement of service-users in the outcomes of their own lives.

These moves reimagined the role of Government as one less about control and more about “shifting the responsibility...to the individual and the market” (Simpson and Price 181). The first clear move towards a policy shift focusing on the needs of people with learning disabilities was the white paper Valuing People released after New Labour took over government office in 1997. Despite its attempts to meet the citizenship, social rights and full participation needs of people with learning disabilities, the policy met with criticism
from both advocates of people with PMLD and the learning disabled community more broadly. Criticisms illuminated that the white paper did not meet the specific needs of people with PMLD due to a weak legal framework. Moreover, its ideology simplified the status of de-institutionalised people by assuming for them a place in society where they would be included where in actuality its framework for “social rights and participation” needed developing (Simpson and Price 181). There was an eight-year time period before the follow up strategy Valuing People Now was developed with the aim of addressing these gaps and located firmly within the Government’s personalisation agenda.

The Affirmative Model

People with PMLD are often described using a deficit medical model that focuses on what their physical and cognitive impairments are and the ways in which they are limited in their abilities. This study acknowledges the value of the affirmative model in disability studies noting both its critiques and validation of the social model. These understand the social model as one that “negates the lived experience of impairment” (Cameron 1) but acknowledge that the affirmative model “should never be seen as a replacement or substitute for the social model” (Cameron 8). The affirmative model constellates around notions of cognitive awareness of one’s condition and then “assertive resistance” expressed as positive statements about it (Cameron 4). I perceived that work needed to be done to further develop the affirmative model in relation to the specific needs of people with PMLD and how they and their key supporters might articulate the relevance of the model to them. This study then, remained in alliance with the social model of disability, which places the burden of responsibility for inclusion, access, and equality with society and its institutions (Goodley and Moore 12; Oliver and Barnes 50; Kiernan 44). Labeling can be imposed on people and consequently remove their right to choose; I am mindful of the sometimes reductive effect of medical definitions. Whilst I was aware that sharing such information could sometimes promote engagement, I have in the main, attempted to focus on what might support participants to work with a participatory arts practice.

The Question of Meaningful Engagement

As part of the implementation strategy for Valuing People Now, a review of adult services for people with PMLD, Raising our Sights created a focus of interest in the barriers people
with PMLD face in obtaining a good quality of life. It was in no doubt that the "major obstacles to wider implementation of policy...are prejudice, discrimination and low expectations" (Mansell 2). Additionally it explored best practice where it had been identified and added further recommendations about the importance of what Mansell termed meaningful day activities “outside the home including work, education and leisure” (Mansell 28). Mencap subsequently adopted the expression meaningful engagement and early indications of the problematic nature of the terminology can be seen in their Lambeth PMLD Project Report. In this meaningful activities are cyclically described as those that are “stimulating and meaningful to the individual” and include community participation “in ways that are meaningful to each person” (40). Here there are echoes of Mansell’s focus on wider and collective opportunities and emphasis on the importance of sensory events and appropriately trained staff. In Mansell’s later writing with Beadle-Brown the term accommodates domestic activity. The authors outline ME as taking three, typical forms:

(1) Doing something constructive with materials (such as washing the dishes, cutting the grass, putting items in the trolley in the supermarket), (2) interacting with people (talking with people, listening to other people talking or attending to them while they show something), or (3) joining in group activities such as watching a ball or running after it in a game of football (40).

These writers outline further granularity, separating the terms meaningful and engagement, advising readers that meaningful activities should include opportunities for the person to develop self-determination and authority “over his or her environment” (Mansell and Beadle-Brown 42), and that engagement is very clearly not passive. The writers acknowledge the limitations of this term meaningful engagement describing it as “a rather simple, even crude, idea that reflects the contrast with the barren emptiness of people’s lives in institutions” (40). Yet what is clear to them is that engagement must be discernible from passive non-engagement by means of knowing the person in question and understanding his or her communication style and preferences. This would, for example, include their assent and dissent positions, non-verbal cues and verbalisations (Choiceforum.org).

Beyond a basic participation in sports, the term ME thus defined did not offer guidance on the potential for other cultural activities to be introduced to PMLD populations; the role that the arts could play was not well understood. In the context of this study then, meaningful engagement suggested a problematic term that lacked clear definition. Yet there is a clear
international drive towards the inclusion of people with disabilities in cultural life; the UN’s Convention on the Rights of Persons with Disabilities sets out its intentions that people with disabilities should, “(a) Enjoy access to cultural materials in accessible formats; (b) Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats” (22). Increasing participation and diversifying audiences is on the agenda for arts commissioners and sites of cultural and artistic interest (Arts Council Wales; Museum Wales; Brighton Museums; Tate). Participation in cultural life is an integral part of the human experience (Mencap.org.uk). However people with PMLD may face barriers to experiences such as those related to the arts (Choiceforum.org; Mencap.org.uk). It is clear though, both in the UK and internationally that people with differing degrees of learning disabilities can create arresting artworks in socially inclusive settings such as those seen through the work of Pallant House and Project Art Works.

The literature reflects the need for a broader, braver vision that pushes the current edges of access and response to arts related activities, access to cultural sites, and opportunities for learning (Hope 2; Lacey and Ouvry 204). The PMLD Network appeals for the diverse needs of people with PMLD need to be met in "imaginative ways" (PMLD Network). Hope argues for an open-minded version of cultural expression that is person-centred and community-centred and defies the prescribed, conventional and predicted (2012). Rather than the "often unresponsive environments" (Nind “Conducting qualitative research” 1) people experience. Practitioners are urged to evolve new opportunities for participants to develop “moments of epiphany in the culture” (Finley 113), via inclusive creative interventions that support risk-taking, choice-making and independence. Nind is clear that the environment should provide the "physical, temporal and emotional space and freedom (for the person) to develop their abilities" (“Conducting qualitative research” 113). The literature persuades researchers to understand the barriers to accessing and responding to the arts, in order that the conditions in which members of the community can create their own culture and the role that the arts can play in fostering these conditions, can be met. This arts involvement requires a careful reconsideration of the predominantly child-specific approaches discussed in the literature (Goodwin and Edwards 11).
Ethical Tensions and Debates

There is a well-developed ethical and legal framework around gaining informed consent in order to ensure safeguards are in place prior to conducting research with people with PMLD. Academic researchers in the UK wishing to work with this group of people must submit their proposals to the NHS Research Ethics Committee for consideration and subsequent approval; this follows initial consent granted by the host university. Voices of dissent evoke reservations that ethics committees may have about “innovative (‘untested’) creative methodologies” present in applications to work with people with PMLD (Boxall and “Research Ethics” 173). Projects may be turned down by ethics committees thereby inadvertently adding to the exclusion faced by people with PMLD who might wish to participate. lancono’s discussion on committees in Australia highlights the "paternalistic stance" (173) that may be inadvertently restricting the opportunities of people with PMLD to self-determination, and be acting in a way that could be considered "exclusionary and discriminatory" (176). Ramcharan and Cutcliffe are clear that “ethics committee members should not either jointly or severally use methodologies as the only locus for their ethical decision making" (362).

The focus on specific methodologies means that the researcher is obliged to navigate different research and institutional cultures, learning about a new terrain of expectations and characteristics as she goes. These will inevitably present a range of opposing or conflicting concerns and development points, perhaps within one institution, assumed or unclear. All of this can leave the researcher at the whim of a reviewer's personal or professional agenda (lancono 174). These factors may be persuading researchers to steer away from this group with a possible impact being the lack of representation of people with PMLD in the literature and an associated effect on the development of policy. There is a clear gap in the literature on participatory arts based research that involves people with PMLD attempting to gain or who have gained the appropriate ethical approval for their work.

Despite the concerns and limitations of ethics committees and their structures, inclusive research practices make claims to a greater intrinsic ethical awareness over those of other research traditions; they assert an innate concern with "power, rights and responsibilities" (Nind Inclusive Research 29). Writers have made a case for the benefits for participants
engaging with research projects. These include improving skills such as the ability to make choices and decisions where these directly impact on their lives, the development of a sense of citizenship and being valued, increased social inclusion and visibility, driving the research agenda towards priorities that interest them, expressing dissatisfaction with services, teaching people about themselves, an opportunity for a new activity outside of the everyday, an opportunity to share their expertise, and improved communication. Aman and Handen stress the importance of keeping the door open for people to participate in research, emphasising the "opportunity" (180); Ramcharan, Iacono and Walmsley and Johnson posited it as a right of citizenship and assert that it is potentially discriminatory to exclude people.

In inclusive research where there is an increasing use of creative methods, discussion is emerging around considering assent within a broader, situated framework. It is clear that the "need for consent is distinct from the need for assent" (Nind “Conducting qualitative research” 8) and that where proxy or personal consent is given, it is essential to continue to assess whether a person is giving ongoing assent. The European Textbook on Ethics in Research describes ongoing assent and dissent positions as “a form of agreement / disagreement that assumes a lower standard of information assimilation, voluntariness and decision-making than that of consent. The purpose of assent / dissent is to respect a limited or developing autonomy” (64). Links to assent and dissent positions are more productive ways of looking at meaning behind behaviours than previous deficit assessments that positioned some communications as challenging or otherwise contrary (Kearney and McKnight 220). However any checking of assent and dissent positions needs to be carried out with sensitivity due to the risks that could be presented through over-persistence. Central to the understanding of these positions are skills and knowledge of care teams and other key supporters. Walmsley (qtd. in Nind “Conducting qualitative research”) reflects the importance of an ongoing conversation between researchers and care teams: "there is unlikely to be a substitute for working alongside people who know the individual well and can draw on the experience of what works with him or her" (8). When working inclusively and creatively with people with PMLD, writers emphasise the importance of staff and practitioners in ascertaining what their assent and dissent positions look like in order to support them to become "in charge of decisions about their artistic creations" (Lacey and Ouvry 210). In order to establish robust research data, capacity
interviews took place with potential participants in this study and dissent positions were ascertained in order to be shared and discussed with participating care staff.

Being alert to participants’ assent and dissent positions gives researching teams recurrent opportunities to test in-the-moment consent. For research ethics committees such as those held by the NHS in the UK, consent is understood as a preference between a simple set of binary positions. Writers have contested this, arguing for consent to be understood as a fluid state, a graduated scale that allows for the “continuum” (Dye et al., 147) of self-determination that is often seen in practice (Walmsley and Johnson 54-59). In inclusive research practices, this reframing of consent is understood in the context where the researcher-participant relationship is negotiated and trust developed over a period of time. Ramcharan and Cutcliffe, in their positioning of 'ethics as process' remind researchers of an ethical way to proceed with vulnerable groups: “the research process should be sustained as with any other human interaction with good intention, in such a way as to respect and not to undermine the person emotionally, socially or physically” (364). The aspirations then of such research processes are to enable participants to emerge as willing parties with their strengths and skills forefronted and supported by the fresh perspectives of their supporters.

**People with PMLD as Agents of Research**

The broader body of literature that focuses on involving people with learning disabilities in research about themselves and the issues they face, includes activities such as the development of a research idea, capacity building to develop appropriate skills or to best utilise those available, design of data-collection tools, and participation in evaluation processes. This highlights the important role that people with learning disabilities have to play in the research process. Walmsley reflects this scope of activity in her statement that "research which includes people with learning difficulties as active participants is now fairly common" (188), and Ware makes it clear that this shift has been "welcome " (175). This move is particularly important for people with complex disabilities whose circumstances often mean they have minimal opportunities to exercise “even the most basic choices” (Cannella 1). In the last two decades there have been two major reviews of the literature on choice and preference within the PMLD population as discussed by Iacono and Cannella et al. Whilst there has been a noticeable increase in the weight of work carried
out in this period, choice-making opportunities are not explored in novel contexts such those outside of daily routines. The status of choice-making and expression of preference as critical factors in the condition of a person's life are seen both in literature exploring quality of life measurements and in disability studies investigating happiness (Felce and Perry 55; Perry and Felce 3; Haigh et al., 29-31). Despite some concerns that people with learning disabilities may not benefit from increased life choices, the literature is broadly in favour of these being made available and linked to the services they receive in addition to "program development and evaluation" (Kearney and McKnight, 220), an exploration of the potential for capacity building for care staff as discussed by Cannella et al. Agreement on, and definition of, quality of life factors began to strengthen in the mid 90s with the emergence of a model that drew together what was a disparate literature. Until this point, the lack of a concrete framework by which to assess quality of life meant that where related policy had been developed, its evaluation lagged behind. In the remaining gap between research and practice, scholars were left with an unclear understanding of how any policy might be impacting on quality of life. Felce and Perry have criticised a lacking of existing categories by which to judge this (63), although they accepted that connections might be made between personal and wider social life.

What the literature made clear is that any assessment should be made within the particular set of circumstances that a person inhabited. Their response to any attached determinants would affect their judgment, particularly where major life events and other life influences disrupt a person's usual level of well-being. Debate also linked moves towards deinstitutionalisation and the associated personalisation agenda with focus on expressions of preference and choice as key foci of study related to this shift in the provision of services (Kearney and McKnight 217). Felce and Perry's 1995 model for assessing quality of life blended categories created by the authors to capture and reflect themes present in fifteen key pieces of literature (62). For them, quality of life was assessed by the coming together of three interrelated elements encompassing subjective and objective factors that are impacted upon by a range of external influences including physical well-being, material well-being, social well-being, development and activity and emotional well-being. It relied on the expression of a person's feeling of well-being, personal values and aspirations. Where quality of life models based themselves on the relationship between a person's needs and demands as constructed by comparison and externally designated measurement factors, there emerged interplay between "objective and subjective facets"
(Felce and Perry 58). Yet life conditions may not always be such that a person would have the capacity to develop an articulation of their aspirations, well-being or personal values particularly in terms of their comparison to those of others, either due to cognitive impairments, social isolation or life experiences that limit opportunities for such comparisons to be made. The literature has shown choice assessments that have been made in relation to a range of aspects including “different contexts…and the nature and number of available alternatives including ones that influence the level of choice given to persons with disabilities” (Kearney and McKnight 231). Attempts have been made to capture choice expressions by individuals in respect of a cross-sectional range of factors (Felce and Perry 60-62).

Operationalisation of the Felce and Perry model for the purposes of this study is possible by limiting its scale and scope: a person with PMLD’s understanding of the factors within this model may occur on a sliding scale, if at all. Instead identifiable factors that impact on the development of participant’s art-making processes and relate to a focus on extrapolating what might constitute meaningful engagement, have been employed within the methodological approach of the study. What must be acknowledged is the role that key supporters play in supporting access to new opportunities and experiences, and where they might mediate the quality of contact. The “domains” (Felce and Perry 61) of Development and Activity and Emotional Well-Being include aspects of competence / independence, choice / control and productivity / contribution and latterly satisfaction and positive affect. The first domain is “concerned with the possession and use of skills in relation to both self-determination…and choice or control” and “the pursuit of functional activities – work, leisure, housework, education and productivity or contribution” (60).

There has been an increase in studies designed to support the development of choice and preference either directly with a participant or via capacity building for staff. Approaches centre on repeated two-choice options and clusters of alternatives offered in the moment; and outcomes include skills development (Kearney and McKnight 227; Haigh et al., 32; Cannella et al., 474). In a study investigating happiness and satisfaction, Haigh et al., worked with learning disabled co-researchers to identify factors impacting on the lives in positive and negative ways (2). Choice and independence were closely linked in the study and it was apparent that people wanted these to have a broad reach into their lives, and to increase this into the future. Whilst people with learning difficulties are increasingly active
and represented in research, the fact that that the literature around research that involves people who have PMLD is just emerging highlights wider social and ethical factors that continue to contribute to the exclusion that this group faces, and to their protracted lack of voice. Although the literature on including people with PMLD in research is fairly young, there has been a commitment to the positioning of choice-making as an important factor in developing good inclusive practices. Stalker locates choice as a “tangible option” for understanding simple preferred options (6). The importance of choice and expression of preference as critical factors in the positive inclusion of marginalised people in research studies has gained ground. The 2005 literature review undertaken by Cannella et al. considered thirty studies about people with PMLD that took place up to 2002. The roles of choice-making and expression of preference are clarified thus:

Where preferences may remain constant or change over time, choice is the vehicle used to express those preferences…while it is important to be aware of and appreciate an individual’s preferences, it is even more important to provide individuals with severe to profound developmental disabilities the means to express their preferences through the use of choice (10).

However, Haigh et al., report a paucity of studies that aim to understand factors pertaining to a subjective viewpoint on life satisfaction by actively seeking out the opinions of people with learning disabilities (28). Their innovative study uncovered key areas of importance as expressed by the 23 learning-disabled adults they interviewed, revealing choice as a key category that was linked to skills development and increased independence. Participants also discussed the importance of being listened to in ways that were directed at their own specific issues. The role of listening gains consideration elsewhere in the literature and the causal pathway between attentive listening and better support of choice-making has been emphasised (Mentalhealth.org.uk 2001; Blanche 76; Mansell and Beadle-Brown 165; Fox and Macpherson 86; Nind “Inclusive research” 23; Walmsley and Johnson 159-161). In reviewing these approaches I noted several principles and practical methods that met at the intersecting areas of this study. I discuss these here in relation to the deep and expansive forms of listening, watching and observing I employed.

In their development of a quality framework for the participatory arts, Artworks Cymru (artworks.cymru) recognised the role of reflection defining this as the periods of time when artist and participants might assess or reveal what has been missed or what might happen next. Other writers advise researchers on the criticality of self-reflection as a tool to avoid
speaking for others (Kemmis and McTaggart 297) and for the researcher to address their motivations (Walmsley and Johnson 9-11). In this study reflection occurred regularly as both a planned and spontaneous activity, with in-workshop observations overlaid by later impression-gathering and deeper contemplations. In their assessment of the measures taken by care staff in their active support of people with PMLD, Mansell and Beadle-Brown saw improvements in the level of engagement with activities where “staff notice and respond to service user communication” and “staff work as a coordinated team to support service users (72-77). Here supporters are encouraged to determine between support that encourages dependency on them, and the preferred option of that which reinforces engagement for its own sake. To arrive at this support I needed to attend to the participants in the study, and to those who would be supporting them. I took a whole-person approach to this attendance by listening, watching and observing: I began to regulate my attention, auditing it to the manners in which different people in the study chose to communicate (Nind “Inclusive Research” 52-57). Adams, working with groups of adults with PMLD through the visual arts expands on her process for listening, which involves:

Using total communication, which is to do with monitoring behaviour, sound, facial expression. It's acute and sensitive and empathetic observation. So that's how we create the right environment to understand and receive communication by people in a working process (qtd. In Fox and Macpherson 116).

The acute, sensitive and empathetic communication described here is echoed and expanded in the notion of “being-with” people with learning disabilities in their visual arts activities. Here listening is also towards gestural and visual vocabularies and emphasis is on solving problems through “making, doing and moving” (Fox and Macpherson 86). Given time to emerge, the expressed choice can be considerable, defying limiting perceptions held by others. In Cannella et al., improved quality of life is a direct consequence of greater opportunities for choice as self-determination is exercised (12). Yet it is important to acknowledge the limitations to the interpretations that can be gained from communications by people with PMLD: choice can be manifested in a number of seemingly oppositional ways including laughing, crying, turning away, kicking and smiling (Kearney and McKnight 228) and Ware reminds researchers that, "it is often only possible to infer (their) immediate preferences" (Ware 175). Expertise gained by Project Artworks in their field-leading visual arts work, positions people with PMLD as often functioning and by extension creating in the moment. However this positions should not cast these in-the-moment choices as
temporary and render their validity as being vulnerable. This study positions such choices as valid if taken into account alongside evidence gathered from key supporters, the setting and the research team. Although researchers must be clear about the degree of interpretation made, many views may limit the potential for incorrect conclusions to be drawn. In their work with a young man with PMLD, Porter et al. support the view that many voices contribute to a clearer picture about a person’s communication stating “the exploration also enables us to question our perceptions and piece together the evidence” (16).

The popularity and potency of choice-making as a reliable intervention in work with people with PMLD has grown in small ways and with it the potential to facilitate self-sufficiency. As Mencap’s *Involve Me* project showed “staff discovered that rather than liking peaceful ‘soft things’ as they had always assumed, Tanya liked surprises and activity. This has changed the way people work with her and the activities she is offered” (Foundation of People with Learning Disabilities 36). Low et al. define participation as “communication that is critical and equal and that enables participants to become aware and empowered to make their own decisions” (52). There is a long game in building capacity for the utilisation of new tools both in an individual’s skills development and in wider institutional and community change. This focus on capacity development is to enable progressive activity, capacity building can entail a range of skills including training staff and developing the conditions for sustainability by embedding sustainable tools within the research setting. In short this promotes “a long-term vision” (Plush 75); and among the benefits for this are the reinforcement of participation in cultural activities as a human right (un.org), and a vision that enables advocacy to emerge.

*The Role of Care Staff*

Care staff and other supporters are central to the ability of people with PMLD to fully participate in day-to-day activities that support the skills outlined above. In addressing the citizenship agenda through its project ‘*A Life in the Community*’, the Foundation for People with Learning Disabilities emphasises the poor quality of day-care provision that many people with high support needs are required to access. It has as one of its key messages that people with high support needs should meet and spend time with people other than paid staff, and engage with them (13-16). Where activities are available outside the home,
studies in the Netherlands show that there is a high risk of them being cancelled due to issues such as a lack of "clear objectives and evaluation criteria in practice (and) insufficient time between activities or staff illnesses" (Vlaskamp and Nakken 107). In the literature emerging from studies conducted internationally and nationally that attempt to investigate the interactions, perceptions and the skill base of staff working with people with PMLD, the criticality of the training they receive in enabling them to interact creatively and confidently with their clients is significant. A group of writers show that there is often a gap or need for further training or different support services to enable this (Goodley and Moore 165-173; Johnson and Walmsley 7-8; Mansell 18). Where opportunities exist for staff to explore new, creative approaches and to put new training into practice there is an increased chance of it becoming integrated. The participatory artist can build bridges into sustainable approaches for working with PMLD populations as staff gain value from seeing "how people react to someone who has different expectations of them" (Lacey and Ouvry, 211).

Attendance to a person’s preferred communication style, including an awareness of their assent and dissent positions, supports staff to work effectively with service users. This can be emphasised through staff training programmes that aim to overcome the problem of staff “generally (ignoring) expressions of preference” (Kearney and McKnight 228). Conversely, participatory arts projects have the potential to draw on social capital available in their networks to blend local capacity, knowledge and norms (Low et al. 61). Project Artworks, although not involved in directly training care sector workers, develops creative tools that impact on their perceptions. Their reach has been extensive gaining recognition from the UK Minister for Culture, Communications and Creative Industries: “it is hugely encouraging to see an innovative visual arts organisation engaging with social care services to support people with intellectual impairments” (projectartworks.org).

Where attempts have been made to train staff in creative methods (storytelling), data collected has been limited to quantitative forms and does not provide an opportunity to hear the experiences and reflections of those involved (Penne et al. 168). Qualitative evaluation of on-the-ground projects has highlighted the importance of witnessing staff and client interactions. After undertaking their Lambeth PMLD Project, Mencap stated that staff working with people with PMLD need more specific training (4). Data of this kind has the potential to further inform the field through insights gained on staff motives and their
experiences of interactions with people with PMLD, thereby highlighting barriers and the content for future training designed to create mechanisms where service users’ ideas can be expressed. Where staff members are poorly trained, support can be compromised and people with PMLD can end up facing a lack of identity and being isolated. Relationships with staff, the training they receive and their empathy skills are all highlighted as factors that are linked positively to the development of communication skills of people with PMLD (Thurman et al. 86-88). Critically a two-way exchange of information and skills will develop better meaningful activities for people with PMLD. Lacey and Ouvry summarise the key considerations and benefits of this approach:

Given the time staff members spend with a person with PMLD and their awareness of communication styles and preferences, artists working with this group of people need considerable active support from carers if they are to be successful. There needs to be careful preparation, common understandings, agreed aims and time given for evaluation. Hopefully staff can learn much from the intensive sessions which can be transferred to their own work with other clients (211).

Best practice guidelines for working with people with PMLD emphasise that the skills associated with effective participation will most likely necessitate repeated practice. The continuation of frequent and regular opportunities to make choices promotes the same skill, enabling people with PMLD to articulate where their preferences may have changed. This may alleviate negative outcomes, as reported by a supporter of a person with PMLD “that’s the saddest thing, people make up her mind for her” (Goldbart and Caton 3). In providing these in ways that meet the person’s communication and environmental preferences, projects begin to synergise with the best intentions of inclusive research practices (Thurman et al. 84).

An emerging literature focuses on the quality, type and frequency of a range of activities that people with PMLD experience and the ways in which these provide opportunities or present barriers to the ways in which they can have influence over their circumstances, surroundings and activities (Zijlstra and Vlaskamp 445). Reported positive gains include the promotion of independence, choice, enjoyment, skills development, community integration and advocacy (Penne et al. 175; Mansell and Beadle-Brown 57-66). Mencap and others have championed the participation in artistic enterprise for people with PMLD highlighting such benefits as the promotion of self-expression and self-confidence and the prompting of social change (Projectartworks.org; touchtrust.co.uk). On-the-ground PMLD
arts groups in the UK work, in the main with children and young people (*Oily Cart; Skoog Music; Bamboozle Theatre*); a few organisations work with adults (Projectartworks.org; touchtrust.co.uk; Soundabout.org.uk). All have developed creative approaches and arts-based tools to engage the PMLD population. However, the visual arts remain under-represented; a notable project working in this area is Project Artworks whose Art in Transition project aimed to join up stakeholders involved in young people transitioning to adult services (Projectartworks.org). In its Arts and Social Policy project, *Tuesday Studios*; it aimed to foster tolerance in the wider community by using a local park as a community setting for making artworks. This last project was targeted at adults, and was time-limited, finishing in October 2013. It was unclear what, if any goals linked to sustainability or whether any meaningful engagement agenda existed for this project. This limited transparency is not uncommon in projects where there is competition for funding from commissioners, and where the working process becomes the intellectual capital for sale to a small market of potential consumers. What can be seen in Project Artworks' Strategic Development Plan is its commitment to art-making through its Art and Social Policy strand of activity where arts is positioned as a "consultation tool within the statutory procedures that influence the lives and care of people with complex disabilities, their families and carers" (Projectartworks.org).

**Inclusive Research in Learning Disability Studies and the Participatory Arts**

The ideals of Paulo Friere to help marginalised people in “developing the ability to name the world and to change it” (Low et al. 51) have been broadly influential in the aspirations of inclusive and participatory research practices. The socially inclusive paradigm of the meaningful engagement agenda had a rapport with thinking and approaches in inclusive research (Walmsley and Johnson 165-168), and those in the participatory arts. The term ‘inclusive research’ is found in the learning disability literature, in inclusive research discussions and in the writings of Walmsley and Johnson (Nind 3). Historically research with learning-disabled populations has been on them (Kiernan 43), more recently the premise and concerns of inclusive research as ones that challenge traditional hierarchies; “it is conceived as research with, by or sometimes for them” (Nind 3). Nind’s summary of Walmsley and Johnson’s discussion on the focus of inclusive research is helpful in locating its serviceability:
Walmsley and Johnson are clear: inclusive research as a term allows for the blurred and shifting boundaries between, for example, feminist, participatory and emancipatory research…It is a term that can be used across fields and disciplines. (3)

The seminal creative life story anthology *Know Me As I Am* performs the epistemological positions of those involved in its conception. These are that knowledge between disabled and non-disabled people is collaboratively conceived and that the former’s “experiences and views...(are) central” to others gaining an understanding of “the world from...(their) point of view” (Atkinson and Williams 5-7). Indeed inclusive participation in social sciences research and in what were initially known as community arts projects (Sutherland 7) has an established reputation for the co-construction of knowledge. It is based on an epistemological position that recognises the construction of knowledge as contextually rich, locally situated and for people with PMLD constituted within their support communities. This knowledge is reciprocal with both researcher and participant taking the role of learner (Nind “inclusive research: where does it leave people with PMLD?” 24); in this it extends the capacity of participants, researchers, communities and institutions. Rolling spells out the focus of epistemologies developed in arts-based research: “(they)…tend to approach knowledge acquisition as occurring within a changing world where persons and phenomena do not always follow the rules…research necessarily involves intervention into that world” (4).

Collaboration is not the only goal for the participatory arts; they have been positioned as “sites for resistance” especially where there is a threat of the “neo-liberal hegemony” (Fье 3) that arises when state-institutional aims can be read as efforts to instrumentalise the participatory arts. Since the Thatcher era, critics have noted that participatory arts have been positioned as a salve for societal ills (Goodley and Moore 4) rather than potential sites of political action that question the status quo. Still, the boundaries between these ambitions can be conceived as porous, particularly where arts research takes place in infrequently accessed locations that are ethically burdensome and challenging to penetrate (Stalker 8). Where participatory arts projects *do* occur in such institutional settings, collaboration and resistance to traditional hierarchies are advanced. In her seminal work in residential institutions for people with learning disabilities, Heathcote recognised the “developed power patterns in hospital relationships” (153) and Stalker talked of staff “who wield considerable power in terms of facilitating or impeding access” (8). Through
Heathcote’s drama practice participants become brokers of influence over their environment where they were “fully recognised as an individual with rights…and rights means giving people the power to affect a situation, to respond to a growing complexity of ways to that situation” (153).

Heathcote’s drama education has some kinship with Matarasso’s definition of community arts; emerging in the UK in the 1970s projects were highly politicised and focused their “collectivist action” on communities (Matarasso 2). Community arts’ more recent reinvention as ‘participatory arts’ has provided ground for criticism around issues such as a lack of political engagement, the downgrading of aesthetic impact, the instrumentalisation of the arts by government for social ends, and the focus on individuals and their problems, as opposed to communities and their collective challenges (Bishop “The Social Turn” 178-180). The terminology around this type of arts participation is not static: “there is no generally accepted set of terms to describe arts participation, but an evolving lexicon of words and phrases that describe how people encounter and express their creative selves and share in the creativity of others” (James Irvine Foundation 6). This has set up intellectual barriers in that deliberations centering on terminology are hindering the growth of the debate elsewhere (Lowe 15), such as around issues of quality, process vs product and labelling.

Other names exist to define the range of practices where art meets communities: socially engaged practice, new genre public art, participatory, collaborative, dialogical, relational, applied aesthetics, littoral, arts and health, therapeutic arts and community cultural development. Where participatory arts practices involved people with learning disabilities they have been, in recent literature called inclusive arts practice and defined as “creative collaborations between learning-disabled and non-learning disabled artists” (Fox and Macpherson 2). Heathcote called her drama teaching practice “a gentle invasion” (154). The problem of the complex terminology in this field is recognised by Lowe: the breadth of language is “both necessary to avoid simplistic categorisations and to reflect the diversity of practice, and problematic because it can lead to confusion” (8).
The Role of the Participatory Arts in Social Change

There is little consolidated knowledge to inform the participatory arts community of its chronological development; there is a lack of “official histories for….relational, social and collaborative practices” (Badham 93). In the last decade, critic Clare Bishop and curator Maria Lind have identified the development of the ‘social turn’ and a ‘collaborative turn’ respectively (Bishop “The Social Turn” 178), highlighting a general trajectory of interest in the field. Additionally there is a growing interest in academic research accompanying this field of arts practices, however, when academic research in the area is conducted, it is grouped under the umbrella term ‘arts-based research’ further complicating the language scene. Despite this, arts-based research provides the “flexible architecture of practice-based theory building methodologies” (Rolling 1). A key feature of arts-based research is that it represents the myriad of research possibilities in different disciplines and locations and with a range of material. Its process includes data-collection via artistic means and dissemination of findings via art-based forms; importantly it is community-facing, acknowledging the non-academic (Finley 73) and the academic (Rolling, 2012) to which it wishes to speak and share its learning. Crucially it aims to "enact its enquiry in the social world" (Finley 73) and echoes the moral aspirations expressed by others to flatten hierarchies of power, knowledge and expertism (Walmsley “Normalisation” 189).

There have been a number of notable projects in the last decade such as Smudged at the Tate Modern, Transitions by Project Artworks and Touching Lives by Touch Trust (Tate; Project Artworks; Touch Trust). The outcomes of participatory practices have included activities, tools and training programmes and have been documented in a range of forms including DVDs. More traditional forms of academic knowing and debate such as journal articles are emerging as discourse communities continue to both grow outward, and merge together (projectartworks.org; Fox and Macpherson 134-161). Participatory arts-based projects have a strong role to play in the development of communities by showcasing not only what recruited participants can achieve but also in what the potential is for other marginalised populations or groups (Matarrasso 37-44; Mencap.org.uk). In their engagement with such work, people with PMLD can break down barriers and build aspirations of others who may wish to conduct research with them, and of those who may wish to participate in future studies. Outward facing goals like these are critical to removing limiting beliefs about people with PMLD as they may usually rely on others to support them
to achieve their goals, and as has been discussed, do not often play an active part in their wider communities. Hope has described the political leanings of such work: “they can be labeled ‘political’ in terms of attempts to change something, express solidarity or engage in protest” (140). Conceptually this work may be embedded in attempts to reinvigorate, empower, build capacity or reuse, and approaches involve partners, stakeholders and others whose engagement with projects causes a paradigm shift or new alliance to develop (Orta and Orta 10). Whatever their process, these art forms are socially active and face towards the body politic; their political interest though does not guarantee that work is considered successful by community members, stakeholders or indeed artists themselves.

Where projects are crowded, not all involved will perceive a positive outcome. Badham reminds practitioners that, “many creative collaborations involve multiple stakeholders with competing narratives and frameworks. This plurality of voices and positions confuses the clarity of vision and purpose usually afforded to the singularity of authorship” (95). Artists attempting to shift participants’ perceptions about an environment may set up or encounter cognitive dissonance; this lack of expectation might lead to far reaching sets of reactions that create a fertile ground for conversation, disruption and resolution (Bishop “Artificial Hells” 11-12). It is not surprising then that practitioners will face anxieties from prospective stakeholders when putting forward ideas that might be deemed ‘risky’. Moderate perceptions can set up obstructions to the implementation and development of an intervention. Macdonald’s *Mouth to Mountain* design meant that she was concerned about the inclusion of “fire, water, horses and taking a large number of people onto a high rock platform at the end of a journey” (Mulligan and Smith 36). Where risk-averse institutions and risk-seeking artists meet eventual success relies on persistence, negotiation, good working relationships and the establishment of mutual understanding over a period of time.

The disability studies, inclusive research and participatory arts literature include debates that take into account key philosophical concerns, which help to locate this study. Historically community arts has presented its practices as having either aesthetic or activist leanings; these are contrasted against contemporary participatory understandings of a “continuum” of practice where such boundaries may be fluid: artists may collaborate on different aspects of projects outside of making the ‘final’ work, or where there may be no focus on ‘final work’ but on the processes involved in projects (Kester *The Device* 1). Implicit to the notions of social change and social control in these intersecting fields are
ideas on power and knowledge; disability studies writers have looked at a variety of models of knowledge and power construction, one of which has been the advancement of Foucauldian perspectives which include the lived experiences of disability including institutional aspects and the shift to inclusionist mentalities and their related ethical concerns (Tremain 1-25). Foucault used the term 'power/knowledge' to signify that power was constituted through accepted forms of knowledge (119) that led to 'truths'. In this he challenged the idea that power was wielded by the few, rather it was a socialised phenomena that contained two inextricably entwined ideas, thus "the structures that maintain one also sustain the other (Oliver and Barnes 30). For Foucault strategies of power were not fixed but existed in flux and in this lay the potential for power to be "exercised" (Nind Inclusive Research 21), leading to the possibility of new 'truths' to be created. Yet these manifestations of power and therefore of the production of new truths could remain out of reach to those with learning disabilities whom the literature positions as having reduced rights:

The rights discourse owes much to Western philosophical accounts of what it means to be a person including, as noted in Article 1 of the UN Convention, a focus on 'reason' reflection and conscience...such a focus relegates those whose reason is perceived to be flawed to a marginalised position where they are seen as objects of charity rather than included as full citizens (Johnson et al.122).

Responses in the literature help to locate notions of power/knowledge for this study: in placing the researcher within the position of 'producer' rather than 'investigator' disability studies discourse has emphasised the researcher’s part in creating, "the worlds" they study (Oliver and Barnes 29). To exemplify Oliver and Barnes’ point to “the domination of able-bodied professionals who tended to stress art as therapy rather than arts as cultural imagery” (104). Taken alongside my emphasis on reflexive practice in this study discussed later under Enhancing Participation and Reflection, I have been cautious about making claims for the therapeutic benefits of the arts practices as outlined in my discussion on Celebratory Narratives. The focus of this study in terms of power/knowledge has been to position traditional hierarchies of power as deconstructed and through this, knowledge as co-developed. I developed this position by privileging the learning I gained from deep listening, watching and interactions with participants.

Kester helpfully muddies the water on the either / or positions espoused by the categorisations discussed above. The neglect of aesthetic concerns has been employed
as a tool for skepticism and distancing, placing artworks as worthy of consideration only if their presentation requires conceptual dismantling and intellectual journeying (Kester *The Device 2*). Kester’s summary of Sedgwick’s discussion on the basis for this positioning of the participatory arts compares her ‘paranoid knowing’ with ‘reparative knowing’. The former is suspicious of ways of knowing that do not conform to their own and the misrepresenting of these; with reparative knowing, the paranoid, “view any attempt to work productively within a given system of meaning as unforgivably naïve and complicit” (Kester *The Device 2*). What is clear is that there is a scale of participatory arts practices each representing an interpretation of the aesthetic, and a range of possibilities for audience participation.

These potentialities are demonstrated by the James Irvine Foundation’s ‘Audience Involvement Spectrum’. Between the binaries of receptive and participatory activity, audience involvement is described in five unique clusters: spectating, enhanced engagement, crowd sourcing, co-creation, audience as artist; the latter three categories move the participant to greater creative control. As co-creators, “audience members contribute something to an artistic experience curated by a professional artist” and as artists, they “substantially take control of the artistic experience; focus shifts from the product to the process of creation” (5). The focus on process over product occurs in activities where the audience is the participating group, and no other ‘external’ audience exists; here the function of the group setting is to ameliorate, share, and enjoy creativity, episodically or as a one-off event. The difference between this and audience-facing schemes is that of critical consumption and adoption by “professional arts programmes” (James Irvine Foundation 14). The participatory arts are replete with binary positions and fluctuating terminology, but in reality the boundaries between audience experiences may be porous, where practitioners may care about both product and process and be alert to critical aesthetic concerns. That debate in, and conceptualisation of, the field is still developing is apparent. Yet increasing interaction with these practices by mainstream arts organisations may begin to present occasions for more nuanced critique to develop (Kester *The Device 3*).

Arts-based projects also have the potential to build bridges into the training that is needed by family members, care staff and other key supporters of people with PMLD (Mansell, 2010). It is increasingly clear that arts practices and activities for people with PMLD have a
role to play in developing reciprocal community relationships by increasing the visibility of people and demystifying their lives (Mencap.org.uk). Recent participatory arts practices also highlight how the art-making process can be employed to develop routes into advocacy and self-advocacy with this group (projectartworks.org.uk), particularly where the arts are clearly articulated as a means rather than an end. Where people with PMLD are making art 'in the moment' (Adams qtd. In Fox and Macpherson 158), this is a supportive position that does not aim to diminish the creative end result but to highlight the potential of a person's creation as a tool for self-advocacy and social change. There are clear recommendations to policy makers about the barriers people face in obtaining a good quality of life and the importance of meaningful day activities "outside the home...(and) in the community" (Mansell 28). The PMLD Network (PMLD Network), in its response to Valuing People Now, strongly revised the focus on day activities to the more realistic and inclusive, "what people do during the day (and evening and weekends)." However, there are few on-the-ground projects and an embryonic literature about people with PMLD undertaking activities described as ‘meaningful engagement’ where there is a focus on choice-making and exercising agency. Where this project-related information is available, is it typically presented as case studies with a primary focus on individuals (Mencap.org.uk).

**Participatory Video**

There are clear tensions in the literature on the utilisation of video as a methodological tool with LD groups. Some studies have been predominantly descriptive and the discourses that have developed have been congratulatory, ignoring the inevitable challenges that arise through the institutional, strategic and academic priorities in what are often multi-stakeholder projects. Complexities include the need for participants to develop technical competence and the role of collaboration in the artistic control participants have in the development of the final story being told (Low et al. 50; Sawnhey 179). The inevitable interceding agencies present a set of possible impacts on the self-representations of people with learning disabilities. These might include the well intentioned ambitions of family members and the funding objectives of day-centre managers; the ways in which videos ultimately depict research participants is critical where those actors are not present to otherwise represent themselves. Simply making video cannot be in and of itself a claim to political change, cultural or paradigm shifts or personal transformation (Low et al. 59-61)
rather claims to change or success must be made against concrete developments such as "capacity and network building potential" (Low et al. 206).

Despite these concerns a good number of researchers support the relatively recent interest in the potential of film as a tool for giving voice and increasing the visibility of people with learning disabilities (Rojas and Sanahuja 31; Buckingham 633) and other marginalised groups (Low et al. 59-61) and in enabling them to express, and others to gain insights into what their views might be (Capstick 269). In advocating for themselves in this way people reveal the potential of the arts as a tool to developing skills transferable beyond the boundaries of the research (Capstick 280). Simmons and Watson deepen this conceptualisation of voice “as something that can be expressed in action towards the physical and social worlds” and highlight the criticality of the role of key supporters in its co-construction (51). This perspective deconstructs a limiting and potentially isolating view of voice as located ‘inside’ a person which, logically followed develops the prospect that they cannot be heard by others, or make themselves heard because of their “lack (of) a point of view” (51). Indeed voice is formed, in part by a person’s expressed preferences.

The literature points to the importance of participatory video in enabling the experience of those who may better communicate non-verbally or with other less traditional literacies. It enacts an equitable, accessible platform for representation and is positioned by Rojas and Sanahuja as “a methodological resource, which permits a more global, complex and comprehensive vision of the personal experiences of the participants” (32). In social research practices, Boxall and Ralph stress the potential of this tool to enable a wider audience to consider the "point-of-view of people who continue to be underrepresented in intellectual disability research" (“Research Ethics Committees” 48). Participatory video is the visual product of a series of interactions linked to contradicting traditions of hierarchies of power, the development of agentive skills arresting to this, and the inclusion of the experiences of the members of the particular research project community. These latter agents act upon the produced video by bringing their edited in experiences to it and thereby contributing to the construction of its meaning.

Low et al. talk about the “ethics of reception” (58) in reference to video media and how and where it is to be shared. When its journey may not be known, it is important that reassurances, guidelines and a clear sense of its purpose need to be established. In this
doctoral study, film had a dual role: it was a tool for collecting and analysing the visual data from the arts workshops which supported the emerging and ongoing understanding of a person's preferences and choices. It also acted as evidence of the art making processes developed by participants, This evidence was developed into the process films capturing MAs when they arose and making explicit through visual form, the often complex conditions that supported ME. Used in this way video was an innovative tool for enabling key supporters to gain insights into what participants' views and experiences might be (Rojas and Sanahuja 31). In this way it was able to stimulate informed responses and generate further buy-in from supporters.

There is an explicit dialogue between the move towards the democratic use of film via the making of participatory video and the political and social use of film for ‘giving voice’ to those with profound and multiple learning disabilities (Rojas and Sanahujas 31.) The ways in which people participate, how film-making tools are employed and the technical competence required to use them, the adaptation of such tools and what, if any other support structures are needed all contribute to the access of the tool and the realisation of the end result. In contrast to traditional documentaries, the films that demonstrate process developed in this study reject the creative treatment of actuality by eliminating traditional procedural barriers to the collection of video data, such as scripting, acting and directing. Rather, films about process are viewed as evidence of the working processes developed, and often captured by participants that made way for their ‘voices’ to be represented. The introduction of GoPro cameras to this study removed the technological barriers that could be faced by participants; by dismantling the need for technical competence participatory video was accessible by people with cognitive and physical disabilities. Plush reminds users of participatory video that this “selecting (of) appropriate technology is an important component in strengthening people’s capacity for action” (80). Outlining a number of participatory video's central features helped to illuminate its potential for research with PMLD populations and for researchers wanting to destabilise, contradict or problematise traditional research hierarchies. Within participatory video the importance of developing trusting relationships with project and research participants provides a conspicuous synergy with the aims of inclusive research practices. Where participants’ cognitive function limits short term memory, a ritual of discovery would enable them to undergo an exploration of her environment, enticed only by, and thereby editing in what is deemed
interesting in the moment as was seen in the case of one of the project participants Hayley.

Although there are democratising claims attached to these processes, and an acknowledgement that they may have an inherent politic in their contradiction of the traditional research set up, Buckingham, discussing Pauwells, reminds researchers to be explicit and honest about any “steering role” (636) they have taken in the research arena. In addition Plush (82) advises researchers that there are limitations on their ability to control the echoes of the final works in filmic form as they reach audiences; indeed here they may be gain new form and accent. Emphases in this study were on directness, simplicity and honesty and the development of methodology through which to develop on-the-ground methods for using video with people with PMLD. This revealed a unique form of participation: a localised view forefronting the lives and roles of PMLD research participants and where they were exerting agency, and in doing so, built a vernacular aesthetic in the final process films.

*Situated Ethics in Participatory Video*

In discussions about the utility of participatory video by marginalised people, ethics is situated and consent recognised as an ongoing process, indeed participatory video is an approach that has been used as a way to “conceptualise and enact participation” (Low et al. 50). The technical barriers that have delimited the possibilities for learning disabled people to access video are aligned to a “technical-rational frame of reference in the Western world” (Capstick 271), which enacts a reduction of humanity to cognitive ability. Rojas and Sanahuja recognise the obstructions that can be caused for people with PMLD by “traditional methodological approaches...(that have)..limited research processes” (31). Capstick argues that the ethical positioning of participatory video requires reasonable adaptations to be in place (271); this is situated ethics extending its reach beyond assent and dissent positions to assimilate and embed inclusive research practices. Adaptations have the potential to go some way towards meeting the need for people with PMLD to experience risk and to become empowered through increased choice and control (Capstick 280). Adopting the values of the principlist ethics of the Belmont Report means honouring notions of respect for persons, beneficence and justice; these open up helpful questions in terms of unnecessary preferencing of technical competence over sensory
knowledge (Macfarlane Chapter 5; Capstick 269). Situated ethics in participatory video extends an opportunity for the inclusive research communities to support participants to mediate visual imagery, enabling the final narrative to fit the goals and experiences of those involved in the study. Final narratives may draw from a range of aesthetic and narrative-making possibilities (Sawhney 180).

Methodological Debates and the Call for Creative Approaches

Commonly, studies involving PMLD populations have focused on behaviourist approaches such as interventions to develop communication assessments, within these skills learned are “functional or adaptive” with stimuli acting as positive reinforcers for aspired behaviour (Simmons and Watson 51). This method places people with PMLD as actors impacting their environments, and is analysed using tools from the quantitative tradition of research. Here the tools are rejected in the pursuit of an inclusive methodology: in their recent work with PMLD children, Simmons and Watson veto a hermeneutic methodology and its focus on a researcher-directed understanding. Rather they attend to shared, co-constructed insights that are in the realms of subjective and objective knowledge and “not outside the world waiting to be discovered or constructed by the mind” (56). Implied is an evolution in skills development where the principle competences required are in the physical world followed by that of the social. Reflecting the aspirations of inclusive research, these modes strive for social change and non-hierarchical research environments.

There is an emerging evidence base that reports on the relational arts practices being undertaken with PMLD cohorts; this has mainly taken the form of photographic books, performances, on-line resources and gallery exhibitions (Frozenlighttheatre.com; projectartworks.org.uk; touchtrust.co.uk). However, the evidence of participatory arts interventions providing a site for academic investigation is embryonic. Both Carnaby and Forster have conducted thematic reviews on the literature about people with PMLD; Carnaby’s review identified only one creative activity, a music therapy study linked to ‘meeting personal needs’ other than sensory room stimulation, which might be considered closest to what the arts would offer; this is a conspicuously small insertion in the overall publication. Although there is no representation of the other arts disciplines in the document, Carnaby’s comment on ‘alternative’ therapies casts some light on the potential for a dialogue between practice and research in the participatory arts; “a wide range of
outcomes has been identified with little reference to the existing research base” (12). Foster's later review includes 14 journal articles in a section on the 'arts and multi-sensory literature' (3). Of these articles, none directly addressed the role of visual art-making practices, one highlighted the same music therapy study seen in Carnaby’s review (Foster 3), and over half focussed on the reinforcement of positive and prevention of injurious or 'negative' behaviours.

Despite the dearth of academic research linked to PMLD arts with adults, there is an emerging call to arms for methodological innovation that is reflexive and acts ethically (Nind et al. 6). Boxall has suggested that the inevitable methodological challenges of such research projects can be bolstered by the selection of “innovative creative approaches to including people”; indeed inclusion is a “moral obligation” (Boxall and Ralph “Research Ethics” 51). Boxall and Ralph and Booth and Booth have investigated the use of Photo Voice that has a tradition of giving voice to those at the margins of society (Booth and Booth qtd. in Nind et al. 13). In the academy, these innovative studies have brought barriers to light. These include tighter ethical regulations and their associated administrative burden, researchers’ perceptions of the challenges of undertaking studies and the potential obstacles in developing relationships with gatekeepers (Emmel et al., 70). The synergising of my participatory arts practice, which included creative problem-solving techniques, provided a useful set of inroads that responded to organisational ambitions for change.

In reflecting on their roles as researchers in Know Me As I Am, an anthology of creative literature by people with learning disabilities, Atkinson and Williams stated “we began to see creativity as an important means of self-expression, as an opportunity to display technical competence, and/or as a form of relaxation” (243) In later work, Walmsley and Johnson drew attention to a growing imperative to create methodologies that included the voices of the members of the community whose issues were being researched (Chapter 3). This shift further developed the challenges and opportunities of including PMLD participants. It identified as a particular barrier the need to make outcomes and learning accessible; for some researchers this has contributed to the slow pace of debate in the area (Walmsley and Johnson 15). There are tensions in what can realistically be achieved in inclusive research with people with PMLD. The degree of involvement in participation, design and control of projects may be limited where communication, intellectual and social
skills are compromised (Nind et al. “Conducting qualitative research” 4-5). People with PMLD are most often functioning 'in the moment' and this has placed limits on the methodologies that can be used to ascertain their views. I was aware, throughout the recruitment process for this study that I would be working with groups of people who were not homogenous in their needs, preferences or communication styles; the methodology I developed would need to be carefully tested in the workshops.

In spite of the concerns researchers might have about 'getting it right', the literature emphasises that "good research is also research that is not frightened to go near people with high support needs" (Nind 26). Nind suggests utilising guiding questions that have been devised by Barton (qtd. in Nind “Inclusive research: where does it leave people with PMLD?” 5), which are: "Who is this work for? What right do we have to undertake it? What responsibilities come with it?" It might be that the undertaking of research through the reciprocal learning we engage in and the analysis we subsequently make changes our expectations around outcomes. Nind discusses a reflection a colleague had about a project: an unexpected outcome was the way in which a person with PMLD had supported analysis and therefore "by prompting reflection (they were) contributing to knowledge" (25). Ware has reminded the research community to be honest about the “limits of what we are…able to do" (178), and Nind has alerted researchers to the quality questions they may wish to ask themselves in their undertaking of inclusive research (90).

Despite potential pitfalls, there is an imperative to ensure that accessibility to ideas and outcomes continues to underpin this sector and contribute to the output of research ideas. A number of positive and supporting factors have been highlighted: environmental plasticity that meets people with learning disabilities at a place and in a context that is right for their preferences (Walmsley and Johnson 211-219), studies that consider “real world contexts” (Simmons and Watson 14), the importance of research relationships developed and sustained over longer periods of time, and the input of key supporters in articulating the position of PMLD participants. In their assessment of the potential of video as a vehicle for political and social change Gaventa and Cornwall state, “through access to knowledge and participation, use and dissemination, actors can affect the boundaries and indeed the conceptualisation of the possible” (70). These opportunities and concerns become central to the investigation of the potential for people with PMLD to participate meaningfully in inclusive research projects and determine what the shape of this engagement might take.
This study was situated in a methodological framework that called attention to the "democratic, ethical" (Finley 435) and active participation of people with learning disabilities. It drew on conceptual resources from the arts-based research literature (Rolling Chapter 2) utilising approaches to practice-led research to conduct a series of workshops that foregrounded the “lived experiences and agency” of the project participants within the project environment (Simmons and Watson 52). The study aimed to define and characterise meaningful engagement. Despite the challenges in defining ME (Mansell and Beadle-Brown 40), it was operationalised for this study within a quality of life framework that integrated two variables: choice-making and expression of preference. These variables systematically appeared within practices attached to the participatory arts and key literature on quality of life and ascertaining the views of someone with PMLD (Kearney and McKnight 219; Ware 175-176).

Methodological focus was given to the management of the workshops, in particular on how day-centre staff and I would able to support participants with PMLD to originate and develop their creative processes and artifacts. A practical framework was established to take into account set up, timings, storage, and clearing the space, but this was kept broad as the participatory arts context was new for the project participants and day centre staff; its breadth enabled the research terrain (Gray and Malins 10) to remain fully navigable as early learning emerged. There were however predetermined foci of interest including the extent to which participants could work independently, environment impacts and relationships, choice-making and the expression of preference, the acquisition of new skills in utilising materials and tools, and emerging art-making processes. By taking the lead from project participants, the practical framework of the workshops supported the development of creative skills which could be used to build relationships and communicative capacity as expressed through choice-making (Cannella et al., 11; Simmons and Watson 17-18).

Arts-based research practices controvert the traditional researcher as the owner of knowledge, instead opening up a space for praxis as a reasoned, ethically informed, socially committed and reflective conversation (Rolling 36). The methodological framework
for this study was developed from an epistemological position that understood the participant's process through co-construction against impressions of authenticity as experienced by key supporters and the community engaged with the research project (Rolling 117). Social policy and policy-facing reports intersect with this study, and their concern with social, daily and community-facing activities are addressed in the literature; there are gaps in what the impact of these on policy beyond local lessons might be. This study has identified a gap in an agreed, centralised understanding of what might constitute ME. There has been no development of local outcomes into a national framework where principles and conditions could inform national audiences and contribute to a sustainable model for working with people with PMLD.

This study was developed, in part, in conversation with the ethical approval process required to gain its approval to proceed. This process presents opportunities, barriers and challenges to those wishing to conduct research with PMLD populations but there is a clear call to arms from writers encouraging researchers to attempt such projects: recent thinking in the field of education studies proposes the positioning of methodologies towards relational aspects of people’s experiences in order to better mediate their life choices (Simmons and Watson xiv). There is a need for the careful consideration of the ways in which research findings are disseminated (Fox and Macpherson Chapter 5) in order to ensure that they are accessible to a broad and intellectually disabled audience. This study took the view that when attention was paid to situated ethics; the breadth of participant’s communication strategies was closely attended to. This ensured that others learned participants’ assent and dissent positions in the research team thereby developing the potential for the participant to teach others about them.
Chapter 3

Methods and Research Design

There has been little academic research accompanying the widespread and cross discipline practice of participatory arts; in order to address this gap in the literature, this participatory arts intervention provided a site for academic investigation. This chapter will review and assess the strengths and weaknesses of a range of qualitative research methods utilised in inclusive research practices and within the participatory arts, and of influence to this study. Methods and approaches for this study drew on participatory action-research (PAR), inclusive research and practice-led research. This doctoral study utilised the case study by design, ethical consent processes and participatory arts approaches to gain an understanding of context specific knowledge. Whilst people with learning difficulties are increasingly active and represented in research, the literature that involves people who have PMLD is just emerging; this highlights wider social factors that continue to contribute to both the exclusion this group faces, and their protracted lack of voice. The recent shift in academic interest as discussed above opens the debate on the challenges and opportunities of including this group and the implications that arise from doing so.

Interdisciplinary Literature Review of Inclusive Research

The blend of research methods utilised for this study emerge from a core dedication to "confront disability by changing....the relationship between researchers and those being researched and the links between research and policy initiatives" (and Mercer 5). Underpinning these methods is a concern for inclusive principles best characterised as tools for promoting "valued social roles" (Walmsley 192) where people with learning difficulties are seen as "potentially active contributors" (Walmsley 188). This makes inclusive research relevant and useful to the communities in which it takes place; it means that it should be accessible to its participants not only in its processes but also in the dissemination of, and access to, its outcomes. In addition, at least a percentage of these participants should be members of the community whose issues are being researched; indeed it is crucial to the validity of the research findings to include these voices (Walmsley and Johnson Chapter 5).
Qualitative research more broadly is aligned to 'getting to know' individuals and supports their evolution as an "expert advisor" (Walmsley and Johnson 51). In disability studies, inclusive research methods are built on three main principles:

1) That research must address issues which really matter to people with learning disabilities, and which ultimately leads to improved lives for them.
2) That it must access and represent their views and experiences.
3) That people with learning disabilities need to be treated with respect by the research community (Walmsley and Johnson 16).

Nind outlines 13 criteria in describing how the quality of inclusive research practices with people with learning disabilities can be judged. Number 12 of these is the question that this study intersects; “Is the research genuine and meaningful?” (What is inclusive research? 90). Inclusive research has its limitations as a method of inquiry; criticisms circulate around the emphasis on observations and other intrusions into the life of the person participating in the study (Walmsley and Johnson 163). This practice-led study, through its investigation of 7 cases, aimed to identify individuality where it might have otherwise been ignored such as in gaining new understandings of Sharon’s established interest in the Diana book. It also aimed to draw together common ground across all of the cases in order to develop future inclusive and participatory arts practices.

**Interdisciplinary Literature Review of Creative Methods**

In participatory arts-based research, methods developed for working with people with learning disabilities are varied and relational; they disrupt traditional research hierarchies and constructions about knowledge:

Unlike positivist approaches to social enquiry, arts-based practices produce partial, situated and contextual truths…The aim of these approaches is resonance, understanding, multiple meanings, dimensionality and collaboration” (Leavy 16).

Here data is collected via artistic means and dissemination of findings realised via art-based forms. Some of the ways in which creative aspirations are woven into research projects is still exploratory and in development but it is clear that some researchers and advocacy bodies recognise artistic activities as constituting examples of clearly defined
and valued social roles (Fox and Macpherson Chapter 5; mencap.org.uk). Indeed, Nind's discussion of creative visual methods in qualitative research underscores the flexibility and equitability of photography as a data-collection method; as discussed the Photo Voice (Wang 185) visual approach has been highlighted as one with a "social and political agenda" (Nind “Conducting qualitative research” 13). With the support of carers acting as facilitators and the enlarging of images so that they can be reviewed with an appeal to the senses, participants become makers who are engaging others in their research process. In disability studies, Boxall and Ralph stress the potential of creative methods to enable a wider audience to consider the "point-of-view of people who continue to be under-represented in intellectual disability research" (“Research Ethics” 48). However, projects making use of creative research methods face ethical approval barriers by NHS ethics committees who might not be familiar with such methods; researchers’ assessment of ethical committees in the UK and internationally examine the criteria for proving 'direct benefit' to the participant, and conclude that it risks "excluding people from research (and) might be considered exclusionary and discriminatory" (Ramcharan 176).

**Research Design**

*Positioning the Study*

As discussed, methodology for this study was based in the qualitative tradition and informed by an innovative mixture of inclusive and participatory action research (PAR) that supported a practice-led focus and enabled me to make use of my tacit knowledge in the field. PAR emerged in the late 1990s where it had an ideological link to research related to marginalised people (Kemmis and McTaggart 273); “participatory research has long held within it implicit notions of the relationships between power and knowledge” (Gaventa and Cornwall 70). It was informed by the traditions of participatory research (Gaventa and Cornwall 70) and the destabilization of traditional hierarchies of knowledge by action research, but differentiated from action research by its desire to focus beyond practice to a better understanding of a particular context in terms of its population (Kemmis and McTaggart 272-284). PAR was aligned to arts-based and inclusive research practices in its change-making concerns and was used in this study to develop evolving practices. Contra to action research that is not always focused on the flattening of power structures in research relationships, PAR looks to those in higher positions to buy into its proposed
actions (Schostak and Schostak 3; Kemmis and McTaggart 292-293). In this, PAR is better aligned than action research to the aims and focus of this study. Imperatives related to access are also found in the intent of PAR; it is built around the commitment to include its participants as collaborative partners in its research processes so that they become fully conversant with them. By placing the site of expertise with these populations, it acknowledges and seeks to give voice to the tacit knowledge they hold. In short, PAR has an emancipatory goal that is realised by engaging a community and putting social change in the hands of the research participants. This adjustment of traditional research roles places a burden of knowledge creation and the sharing of research findings on participants. In the context of this study, the adjustment presented interesting challenges in the balancing of an on-going dialogue that addressed the tensions between group problem solving and leadership, shared power and facilitation.

PAR was modeled on a spiral of iterative self-reflective cycles similar to those found in models of action research which were often interpretive and constructivist in their approach (Wisker, 2008; Kemmis and McTaggart 281). By their self-reflective nature these cycles implicated an emphasis on understanding the ‘real world’ of practice such as the contextualised factors that impact it, and whilst PAR explored the concrete, the current and the particular, what set it apart from other forms of action-research was its emphasis on the collaborative. For this study the location of collaboration was positioned not in art-making practices but in research design and relationships, to what happened in the workshops: “if practices are constituted in social interaction between people, changing practices is a social process” (Kemmis and McTaggart 277). As it was conducted in a dining room, a place where participants congregated, this study utilised ongoing action and reflection cycles typical to PAR. It involved cycles of planning, action, observation and reflection that enquired about key questions: what people do; how do people interact with the world and with others; what people mean and what they value; the discourses in which people understand and interpret their world (Kemmis and McTaggart 279).

PAR was defined by a number of characteristics also found in action-research. Kemmis and McTaggart conceptualised and progressed the traditional action-research spiral model along social and individual lines by presenting seven characteristics specific to PAR. Via social process an individual enacts her social world; through its participatory characteristic PAR was a process that was critically self-examining and self-facing and it was practical
and collaborative in its emphasis on positive reconstruction of social interactions. PAR’s focus on limiting dissatisfactions created its emancipatory character; it was critical in its assessment of the social media and social relationships that were used to describe an interaction with the world. It was reflexive in that it opened up deliberate discussion based on actions. In this it encouraged communities to critically question both the ways in which they participated and which external limitations may impact their involvement in the study. It was transformative of theory and practice through a mutually weighted dialogue between these factors (281-284). This study understood participants as collaborators in its iterative research design where their ongoing choices delineated the path that would be travelled along. This “participatory condition” closed the gap found in traditional research relationships (Montero 132).

**Limitations of PAR**

Warnings have been made against a focus on celebratory narratives and the risks inherent in the “social location of the researcher” (Macfarlane 59) that could create bias, inflating the change-making potential of PAR. Kemmis and McTaggart have held themselves to account in four key areas where the impact of their own research has been reevaluated: empowerment, facilitation, research-activism dualism and the role of the collective. They have discussed their own reflections on this and have learned that aspirations for empowerment must be tempered by a grounded, realistic view of the research context which may be messy, unpredictable, resistant or reluctant: “in real settings….individual and collective change (is often) extremely difficult to effect” (285). Although enthusiasm can be a powerful motivator for the researcher there needs to be an appreciation that they cannot create the changes they seek alone or simply through will. The traditional research roles and their association with detachment and neutrality emphasise the Other (Said xv), thereby risking the potency that researchers have to impact social change “as indispensible advocates and animateurs….and not just technical advisors” (Kemmis and McTaggart 286). This study was necessarily shaped and informed by a kaleidoscope of voices; the democratising emphasis on the ‘collective’ was made relevant, transparent and accessible.
Case Study by Design

The practice-led part of the study was composed of a participatory arts practice-led intervention comprising of 20 weekly workshops. There were seven cases, each bounded by the intervention, its location and timing; the project participant group was an intensive sample of adults with PMLD and their attending care staff. The approach to sampling was adopted from such fields as education (Simmons and Watson 143) that narrowed the small, specific field of PMLD. The research design enabled an ambitious mix of data in the following categories: film recordings, photographs, semi-structured interviews, questionnaires and artifacts. In this doctoral study, the conception and operationalisation of a case was informed by thinking in the social sciences: following Ragin and Becker, cases were viewed as objects of investigation similar enough and separate enough to permit treating them as “comparable instances of the same general phenomena” (1). The seven comparable cases shared a set of available materials and a range of environmental factors such as furniture, lighting and the occasional utilisation of the intervention space by non-participants. In their analysis it was expected that individual cases would disclose specific additional environmental, personal and relational factors.

The context for investigating the possible ME of individual participants was “an analysis of social phenomena specific to time and place” (Ragin and Becker 2) but the characteristic conditions for meaningful activities to occur varied for each case. It was clear that time was needed to get to know and work with people with PMLD and the preferred methods of communication of each participant (Mencap.org.uk) and that it was critical to focus on opportunities to learn about the broad range of possible conditions described above. Where bounded by an on-the-ground, time-limited and creative intervention, case studies reporting on arts projects with learning disabled groups have tended strongly towards a focus on individuals and disability arts organisations (disabilityartsinternational.org). This study followed the precedent set by the practice-led literature but also addressed a gap in the literature through discussion of cross-case categories.

The literature supported the potential of film as a tool for giving voice and increasing the visibility of people with learning disabilities (Rojas and Sanahuja 32) and in enabling them to express, and others to gain insights into what their views might be (Ware, 2004). In social research practices, Boxall and Ralph have stressed the potential of this tool to
enable a wider audience to consider the "point-of-view of people who continue to be underrepresented in intellectual disability research" ("Research Ethics" 48). In addition to these perspectives, a range of opinion from proxies, family members and other key stakeholders informed the research findings. These opinions were built into the case study analysis.

**Enhancing Participation and Reflection**

*Participatory Dialogues*

Participatory Dialogues were developed as a research method after Spaniol’s discussion of them in relation to supporting the development of stakeholder relationships in art therapy settings, and the description of them as an exchange of “experiences, perceptions and perspectives” (1). For the purposes of this doctoral study, Participatory Dialogues functioned as vehicles for *listening in*, strengthening relationships between myself and the staff team and developing trust. Dialogues acted as collaborative processes that aimed to “precipitate…social change…(and were) responsive to pluralism….co-generating relevant knowledge that results in action” (1). I encouraged dialogues to occur within and outside of the workshop space around dining tables and into corridors, the garden area and other parts of the day centre building. In order to facilitate Dialogues, I used open-ended questions such as:

1) *How was today’s session?*
2) *What did you learn today?*
3) *What do you think the other staff will take away from today?*
4) *What do you think was meaningful to the participants today?*

These types of questions did not limit the scope of potential responses but instead supported respondents to recall a broad range of information. I reflected on responses later in my reflexive journal, not simply as descriptions and observations, but in order to use them as “thick descriptions” (Denzin 33) and “a place for reflection, analysis and interpretation” (Clifford 52).
Visual Arts Materials

With their emphasis on “show rather than tell” (Nind “Conducting qualitative research” 13), visual methods support people to speak for themselves where words may be unavailable, problematic or undesirable. The project aimed to develop artistic vocabularies and processes that took as their starting point materials readily available in the day centre such as paint and some drawing equipment, as well as utilising others that were perhaps not immediately recognisable as having material potential for art-making, such as plant matter. Materials were varied and tactile and included charcoal, paint, air drying clay and a range of different papers; primarily materials would be purchased that were non-toxic and therefore safe to use whilst of a high artistic quality. For some participants, there were already established relationships with arts materials but the nature of these was not always understood; I could not always ascertain if they have been liked, feared, mistrusted or enjoyed. There are challenges in using material sensory stimulation with people who are tactile defensive and may respond by "rubbing, scratching, negative expressions, withdrawal, or avoidance " (Baranek and Berkson 1). Yet people with PMLD need "stimulation, variation and challenges" (Vlaskamp and Nakken 107) and tactile and sensory experiences are a critical part of the established practices of a range of creative projects working with people with PMLD in the UK and internationally. In this study materials were introduced slowly, using in part, deep listening to establish situated consent and using this as a way of taking the lead from the participant.

Video Data

Video had a flexible role to play in the research for collecting and analysing data as well as contributing to the creative outcomes of the project by supporting the creation of categories for coding. The multi-functionality of the video data combined with the research question and aims of the study meant that the sole use of traditional film cameras would not provide a sufficient tool for collection. Instead, data was planned to be collected using a selection of cameras including HD video, GoPro and an iPad. Access to the use of GoPro and HD Digital cameras presented an opportunity for participants to ‘edit in’ their experiences through their isolation of these in the viewfinder. Collected video data was used for analysing and triangulating analysis of ME in the workshops and supported recognition of this. Care staff were invited to periodically view film clips in order to ensure a robust
assessment of the data including triangulating assent and dissent positions, choices and new activities. I also used triangulation sessions to feed back emerging analytic insights for checking and revision and to develop a robust project by ascertaining the views of supporters and staff in order to limit the risk of the "subjective interpretations" (Ware 175). Video data also formed the basis of a series of process films developed to create a site for understanding and sharing the ME of participants. Additionally the camera offered an opportunity for participants to turn the gaze that so often confronts disabled people onto others and themselves, in ways that promoted others to view them as agents and self advocates.

These research design priorities impacted the ways in which the "focus and framing" (Heath et al. 11) of the video data was planned, and on choosing the equipment that was needed to record the workshop activity. The methodological position for the study was that the data would generate categories and themes; this influenced the decision to record the entirety of the workshops for the first three weeks before reviewing other possible approaches (Heath et al. 11-15). The fish eye lens and non-static point of view of the GoPro cameras that participants were invited to wear presented both challenges and opportunities in viewing the data collected. The GoPro can produce unstable images that sometimes lurch when the focus of a particular scene or item is not held. Yet the characteristics of these images present viewers with uniquely personal points of view. In doing so they supported the creation of a more equitable, inclusive research context (Spaniol 3; Macfarlane 26). This context included formal carers who had “at least part responsibility for ‘fighting the corner’ for people with PMLD (Kiernan 46) and as such fitted with the methodological focus of the study. Process films went beyond the traditional parameters of documentary in that they invited the participant to engage in their own camera work thereby actively undertaking the collection of footage.

*Process Films*¹

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¹ I acknowledge the Norwegian creative agency with the name ‘Process Films’; however, I am not referring to this company or claiming they have produced the films for this study.
The films created as part of this study set out to meet a number of objectives, including raising the expectations of the abilities of the research constituency to an audience of family members, care staff, key supporters and to an academic audience. Films were designed as an intervention in the literature that would enable participants voices to be heard and their experiences to be made visible. In particular they aimed to illuminate what constituted ME for the participant via the choices, preferences, rejections and relationships woven through their art-making processes.

These films about participants’ unique creative processes combined perspectives from GoPro and hand held cameras. The resulting narratives focussed on the meaningful engagement of the participant as demonstrated by themselves and understood by their supporters, and myself. It was important that films about these evolving processes did not simply develop a celebratory narrative, rather that they showed effort, focus, where new skills were learned, and what types of support had been critical to helping them make their work. In essence the films aspired to tell a varied audience of supporters about the person and would provide insights about activities they prefer to engage in, in ways they preferred to undertake them.

The naming of these films as ‘process’ was to simplify and make accessible their content across the disciplines this study intersects, where audiences might be unfamiliar with either the academic content or practice-led aspects of this thesis. The films were deliberately left without sound in line with my previous practice in this area, which has attempted to make films as inclusive as possible.

*Reflexive Practice*

Reflections on my practice were made through written texts in the form of a reflexive journal and were also undertaken via visual means (Fox and Macpherson Chapter 5; Butler-Kisber and Poldma 4; Gray and Malins 3). Collage is a well-established art form but has gained ground as a qualitative research tool and interest is growing in its support for the researcher to “work in a non-linear and intuitive way by arranging image fragments that reveal unconscious connections and new understandings” (Butler-Kisber and Poldma 2). Within this doctoral study, collage is positioned as a reflexive tool that I used in conversation with myself; it is not positioned as a body of work whose artistic merit is
accountable within the final thesis. This arts-related mode of inquiry satisfies “different kinds of understanding grounded in direct experiences…(which)…counters hegemonic and linear thinking” (Butler-Kisber and Poldma 1). The ways in which collage elements butt up against, play with and inform each other and the qualities of scale, palette and composition gave new depth of meaning to my research experience. Butler-Kisber and Poldma suggest working in series on small-scale collages as a way of exploring different aspects of a development or analysis (3). I utilised visual collage and journaling practices in order to maintain a reflexive position in the study and to develop artful ways of knowing.

Ways into collaging enquiry included beginning with a clear starting question to explore a particular issue and allowing stories to emerge from a selection of collage-material options. Commonalities across collages would be viewed and assessed for the deeper concerns, anxieties and potentialities that arose. This study builds on my existing collage practice that used collage for both academic and practice-led enquiry supporting critical insights to be made; these in turn enabled better understandings of relational, environmental, conceptual and strategic concepts when they were emergent. My written journaling practice included a layering of reflective ideas combined in a single text and was created by a collection of ‘mobile’ written thoughts that have been developed in transit and later photographed. In an iterative cycle of reflection, these notions were further commented on in a final text that provided coherence to the ideas without compromising their non-linear nature. This capturing of text snippets enacted the cyclical nature of participatory action research: in the journaling practice, these snippets echoed descriptions of memos as a series “of pauses in the work” (Butler-Kisber and Poldma 2), fleeting thoughts captured in shorthand that opened up or developed key thinking in lines of enquiry. Additional reflexive practice also took place within the network view function on Atlas.ti (Appendix G), which allowed further non-linear relationships to evolve out of the data. There was a symbiotic relationship between the collaged, networked and written elements of the reflexive strategies used for this study respecting the value of curiosity in the development of new thinking.

**A Reciprocal Learning Event**

Mansell and Beadle-Brown have observed that staff working with people with PMLD play a critical part in supporting them to fully access activities: “for people with severe and
profound intellectual disabilities receiving services, it is axiomatic that in many respects, their quality of life depends on support provided by staff” (13). Each of the 7 participants in the study was accompanied by members of staff from the day centre. The research design for this study involved this group of staff as participants and as such, accounted for their contribution to the data set being collected via their formal consent to take part in the project. Consequently, they inhabited complex roles as participant, supporter and co-researcher.

These complex demands on staff meant that they would need to build capacity in terms of participatory arts approaches and principles, a broader understanding and demystification of related arts practices, and a focus on sustainability of approaches or a legacy for the project. Projects such as the South London Black Music Archive (tate.org.uk; disabilityartsinternational.org) make it clear that considerations of sustainability are critical to the credibility and value of inclusive arts “in order to ensure that real partnership and a respectful and reciprocal exchange” are maintained (O’Brien et al. 19). It was critical that the expertise and opinion of staff informed the project design, thereby maintaining as inclusive approach to the study as possible. In order to facilitate these objectives and begin the formal recruitment drive of staff into the project, I planned a reciprocal learning day where myself and staff could share expertise and knowledge. This would also inform the completion of the NHS IRAS form (Appendix B). A series of carefully planned arts-based exercises focused on increasing staff familiarity with a range of arts tools, materials and approaches. In an exercise that exemplified non-verbal ways of negotiating and being ‘led’ by a collaborator and encouraged sensitivity to non-verbal cues, staff were invited to engage in making large scale Indian ink drawings on sheets of cartridge and brown paper (Photo thesis). Partners came to mutual agreement on the direction of the ink and the final resolved drawings. Further exercises explored the potential of crushed graphite, chalk and charcoal through exploration of their malleability and permanence. Care staff experimented with rubbing through, rubbing out, layering these materials, adding water, and applying them with tools such as a brush, sponge and by hand. Short series of work were made on accordion sketchbooks and larger sheets of drawing paper enabling staff to experiment with scale and the effect of timed activities. In the debrief, the group explored their feelings around their shared performances of making and the feelings they might have about the display of their artwork in public and shared spaces. Responses showed that staff felt
some ownership towards the artworks they had made and this promoted reflections on how participants might feel:

Mark: I wouldn’t want this on the corridor and everyone seeing it without being asked. I can see that we shouldn’t just assume service users would want that either.

Bree: I felt a bit embarrassed when we were working on that table, I can’t draw! But then when people said nice things about my drawing I felt really good.

Steve: I really enjoyed it, love getting my hands dirty but I did get some charcoal on my jeans, it goes everywhere doesn’t it! We’ll have to make sure everyone can be covered properly.

Julie: Can I wear gloves? I don’t want paint to get on my hands. I can see that some participants wouldn’t like it either.

In addition, the group was invited to consult on the staff-specific consent and information sheets required by the NHS. Alongside building capacity, I planned to learn as much as I could about the ways in which staff thought we might work together. In this way I could use the IRAS form to evidence a commitment to creating a rigorous collaboratively informed project design that put people with disabilities at the heart of the study. In order to de-emphasise traditional research hierarchies, we agreed to name the day ‘a reciprocal learning event.’ It was imagined as an opportunity for peer sharing and development; as well as sharing my own expertise I took the role of a learner in what Nind describes as “a kind of apprenticeship or knowledge exchange model” (What is inclusive research? 62) where I focused on staff as “experts by experience” (63). This focus enabled me to gain specific information such as the known preferences of potential project recruits in respect of creative activities and to open up a space for global learning to occur where other, useful information could be captured, such as a person’s experience of working in a group. The sharing day enabled the first building blocks of what Osterloh calls “amplifying dynamics” (12) to be put in place. This mean that “all partners contribute to a project and mutually reinforce each other” (12) and for the study this meant the need to be clear about the jobs each person might take on throughout the project but also that roles may shift due to changing priorities.
Evaluation of the day was via ongoing commentary and final thoughts were collected on sticky Post-it notes for collection. Comments were grouped thematically and concerned enjoyment, interest, new perspectives on, and understanding of, art making, new possibilities for working, positive anticipation of the research project, and a connection to, and reaffirmation of, political aspirations. Staff engaged with and learned about each other in new ways, using materials in risky, playful ways that opened up visual lines of enquiry such as the layering of paints with crushed graphite (Fox and Macpherson 87). This method enabled staff to make ‘messes’ and perceive them as constructive, not needing to be defined as good or bad but as positive beginnings or as finished pieces that could be enjoyed for the journeying they portrayed. Although helpful to staff in many ways, the method was limited in its inability to truly teach staff about the power of the projection of their expectations on participants, particularly in terms of timeframes and notions of success. In his reflection on mentoring a person with PMLD for eighteen months ahead of the 2010 Project Artworks exhibition ‘if a picture’s worth a thousand words’, Colley recalled having to “overhaul” his assumptions “particularly with regard to time and how long or how slow something may take to get done” (2). There were practical problems with the aims of amplifying dynamics due to unexpected staff changes, and motivational and attitudinal factors that created barriers to this desired step change for a new distribution of power in the research space. This necessitated a development of an in-situ training-sharing regime that had some impact upon my resources, mostly in terms of time.

Opportunities and Challenges

This project design considered the opportunity to "rewrite culture" that is presented when marginalised and excluded people demonstrate their perspectives in artful ways (Finley 74) and positioned research participants as “creators of culture” (Montero 141). These were the starting points for a final design that built into it the intensive periods where participants constructed the form and content of the workshop data. In order for this to occur there were places in the overall shape of the project where its design could be said to be emergent. The emergent elements of this project sat within a pre-developed framework that 'held' safe working practices, the key milestones in the lifecycle of the project, and other practical considerations discussed elsewhere in this thesis. Arts processes are often emanant: as participants explore and gain an intimacy with arts
materials the unfolding dialogue informs the process for art-making. In relation to this doctoral study, staff members and the researcher supported participants to engage in these processes and develop them further by following their lead on how this might happen and suggested ways to support this.

Participants recruited to this study were adults with PMLD who, it was thought, might not be able to give informed consent to take part; this necessitated an application to the NHS whose approach to granting ethical approval has been shaped by historical misconduct in medical research, including experiments on vulnerable people (Macfarlane 9-10). This has led to the introduction of increasingly tightly controlled ethical approval processes for studies with participants who cannot consent to participate (Lancioni et al., 392). The rigour and tight parameters of how medical research culture is played out in the IRAS form, the aspirations of inclusive research for social change and the rethinking of traditional research hierarchies, acted like oppositional magnets pulling against different parts of the project design. Fox and Macpherson summarise: “the way in which ethical consent forms have to be written...may be somewhat at odds with the process of engaging with people through arts-based approaches” (158). Despite these challenges within this study, the effect of these influences, research cultures and their associated priorities led to particular elements of the project design gaining emphasis. Among these was the development of new thinking about ways in which video could be used in the project as interest in, and use of film, has co-occurred in the social sciences literature and in participatory arts practices both in the UK and internationally. Film has been variously positioned as a tool for comparing the experiences of a disabled and non-disabled person, to giving voice to the preferences and to increase the visibility of learning disabled people, and to support those transitioning from children's to adults services (incurve.jp; projectartworks.co.uk). NHS concerns around the use of film in research focus on their commitment to anonymity and confidentiality; an additional implicated concern is about film finding its way onto the Internet, though this is commonplace in on-the-ground arts practices.

In addition to being considered through the University’s own research approval process, proposals that require ethical review because of their work with people who may lack capacity to consent are subject to Tier 4 scrutiny via the Integrated Research Application System (IRAS) and subsequent interviewing panel. Engaging with the ethical approval process creates factors that impact the final shape of the research design; researchers are
obliged to determine a person's capacity to be able to consent to participate in research, and it is possible that they may not have any experience of undertaking the assessment; there are no specific guidelines on this for arts-based projects. In addition, in learning disability research where there is an increasing use of participatory methods, a discussion is emerging for considering the capacity to consent within a more flexible framework and as situated. For the case of this study, consent was ascertained prior to the workshops and subsequently monitored and checked moment by moment as discussed in this thesis. In order to find a balance between the aspirations of inclusive research practices and the strict privacy demands of the NHS, this study took the position of not setting up a visible web presence, or of sharing any of the project outside of the academy or related practice or in any way disseminating the study in ways that could compromise the anonymity of the participants. Indeed, without this position it is anticipated that the project would have struggled to gain NHS ethical approval. Instead the midway position was to enable password protected viewing of process films and other imagery for appropriate parties to have access.

Although there were 7 project participants attending each workshop, it was planned that each person would work individually with myself and staff to collaboratively design the direction of their individual workshop experience including choice of materials, scale of work, and other decisions such as when a piece was finished and when to have a break. The materials available during the workshops offered participants a range of sensory experiences in terms of light, temperature, consistency and sound. They were introduced slowly, sensitively and expedited through participatory dialogues. Iterative research designs are an established integral part of action-research methods as lessons learned are fed back into the collaborative design process. There were tensions though in what could realistically be achieved in inclusive research with people with PMLD; the degree of involvement in participation, design and control of projects was limited where communication, intellectual and social skills were compromised. In addition, and as has been rehearsed elsewhere in this thesis, care staff were critical to the ability of people with PMLD to fully participate in day-to-day activities. I had anticipated that the undertaking of research through the reciprocal learning staff and myself would engage in and the analysis we would subsequently make, might change our expectations around outcomes. This reflexive position enabled me to make developments in practice as well as conceptually: a reconceptualising of one of the participant’s reported over-attachment to a particular book
was reconsidered and then investigated. This led to a new clarity that she held a passionate interest in the book and was making clear choices in particular pages that held her interest.

Summary

Nind has invited researchers to think reflexively about their inclusive research practices, and in doing so to be prepared for a change in our expectations of their outcomes. The methodology I developed for this study aspired to meet the encouragement for creative research approaches in the literature. Whilst I initially conceived the films I would develop for this study as artifacts, there was an increasing sense that they could speak to the construction of Finley’s “situated and contextual truths” (28). I began to understand that the films could have a functional use in sharing their ‘truths’ with other care professionals; the films could be used as an intervention for training others to develop understandings of and new meanings from the experiences and actions of members of the PMLD community. They could also be used to inspire others who might wish to undertake creative activities and serve as a vehicle for sharing participant’s achievements or experiences with key supporters. To increase their accessibility, I removed the sound from them. I treated the photo thesis in a similar way by removing written language from it except for the accessible foreword and the names of the participants. I perceived it and the films about process being used in conversations and as a site for questions, comments, observations and appreciation of the achievements and abilities of the participants.

The sharing, reciprocal emphasis in my methodology was a lifeline to gaining valuable insights not only about participants, about also the Day Centre itself and the challenges it was facing. It set the tone for strong working relationships to be developed and critically enabled the triangulation sessions to work effectively. Staff were often incredibly busy and attendance of the triangulation sessions was an additional task, but at least 4 people attended each. The emphasis on a two-way relationship that had been developed in the reciprocal sharing session was played out in these sessions; staff were not reluctant to speak and share their expertise and insights. The strategic approach to organising, reducing and re-constructing data supported the creative, participant-led, inductive methods of the study. The use of a range of software provided the ideal mix of tools with which to creatively explore the research question, its aims and objectives.
Chapter 4

Mapping the NHS Ethical Approval Process

An Intertextual Reflection

I had a late afternoon meeting with an NHS research ethics committee (REC) at the National Hospital for Neurology and Neurosurgery in London. The hospital was flagged as one that would provide an interview panel for studies involving 'adults who lack capacity to consent' and I was anticipating a high level of questioning and scrutiny of the IRAS application I had submitted. It is right off Russell Square in West London and when I approached, I saw a line of ambulances and one or two patients in wheelchairs outside. It is a traditional looking redbrick place, large and very imposing. The smell inside was overpowering: vying for my olfactory attentions were, in equal measures, bitter antiseptic and something stale and musty. Both smells made the expansive building feel airless and added to my growing feeling of anxiety. After wandering about trying to escape them, I found some quiet space in the darkened Chapel where I tried to refocus on the research interests that had bought me here. It surprised me to discover a strong sensory aversion to the environment and I was reminded of previous, sad experiences in such places. What is not surprising is that these REC meetings are often held in hospitals given the research cultures traditionally affiliated with applying for NHS ethical approval. Yet the process of engaging with this can present challenges to researchers not attuned to these disciplinary cultures and their characteristics. Discussions in the literature describe the experience of tackling ethical approval processes as taking on an “alien” culture (Macfarlane 25) and expose the complexities of “managing ethics” in inclusive research where there is only “emerging guidance” (Nind 87).

RECs like to see PhD students being accompanied by a member of their supervisory team and the simple activity of having a coffee to discuss any last minute thoughts proved very helpful. My supervisor and I undertook our coffee stop before dutifully waiting outside the Old Boardroom where the meeting was to take place. There was a sense of the surreal in the opposing scales of its grand doors against the very low, and rather small chair I found
myself in, and this proved to point to humour in the day. The meeting started promptly and we were ushered into a wood paneled, sizeable room with a large oval table around which sat 9 people. Despite the size of the room and the large window off to the right, it was rather dark and there was the same stuffy air in the room. We were invited to sit at the head of the table and with very little ado the Chair was busy introducing herself and asking us to do the same. This all happened before I had a chance to put my coat on the back of my seat and sit down, and I felt very rushed. After we had introduced ourselves I started answering questions. These came from the Chair in a rapid, albeit friendly manner. I had anticipated introductions to the rest of the Panel but these did not happen and my feeling was that there was a very keen interest in keeping to time.

It was a little other-worldly to be inside the REC Panel. There was a tension between what I already perceived my research to be and the demands of proving this to the Panel. Nind has neatly summarised the way in which inclusive researchers perceive their work in relation to ethics stating “the drive for inclusive research is a drive for ethical research” (30) and this notion of an inherent ethical concern is reflected by Dye et al., (4). However, it was clear to me through the process of making my IRAS application that the ways in which ethics were forefronted in my inclusive, arts-based practice differed from what the immediate concerns of REC Panels were. The set up of the Panel alongside the quick fire questioning style created a scenario where I felt I was in defence of the research proposal rather than participating in a discussion with explanation where needed. Writers have articulated the complexities of presenting inclusive research to ethics committees, both where creative methodologies and people who may lack capacity to consent are involved. They have noted that the conservatism of ethics committees can be paternalistic creating the risk of potential exclusion from research for those who are most vulnerable. Yet there is a call to arms, an acknowledgement of the specific needs of people with PMLD, a group that are not homogenous in their preferences or communication styles, and the challenges of developing "innovative, creative (methodological) approaches" (Boxall 8).

Researchers considering ways of including people with PMLD in research and supporting them to contribute to knowledge are making a case for rethinking traditional research ideas. Yet researchers are alert to the reality that the introduction of such methodologies may serve “to compound ethics committees’ concerns” (Boxall and Ralph “Research Ethics Committees” 176). I knew that my research proposal was one that could be
perceived at best as innovative or worse, risky. I realised that my own misgivings could be echoed in the experiences of others, a contributing factor in the reluctance to engage with similar research governance exercises with people with PMLD. My supervisor was taking notes as I fielded the questions, something I was glad we had arranged as the speed of the meeting would have resulted in my missing some of the detail when attempting to recall it later on. The Chairwoman said that the panel was impressed by my level of public consultation for the project. Part of this had included my collaborative development of the project’s consultation documents with care staff at the day services where I would be holding the workshops. The other part of this consultation was a group of interviews with learning disabled artists about some of the aspects of the research that I anticipated the REC would find contentious. This included talking through how people would feel about being filmed and these films being shown to a wider audience. My consultation exercise had also included attempts to open up a dialogue with some of the gatekeepers attached to the organisation where I would run my study. This was in order to proactively address some of the challenges presented in attempting to recruit people with PMLD. Gatekeepers, the literature has shown, may sometimes wish “to protect, rather than allow for the dignity of risk (or) resist participation for fear that services might be jeopardised or negatively evaluated” (McDonald and Kidney 28).

In addition to the positive feedback, there were questions that centred on risk, privacy and participants’ freedom of action. The Chair wanted to know how I would support a person who wanted to leave the workshop, perhaps because they were distressed. I talked about the lovely light and bright space we would be working in and emphasised the large, flat garden that we would have access to that could serve as a space to relax and retreat. It has always been clear to me that the REC’s interests would be on risk, anonymity, informed consent and confidentiality. This was a constant in the IRAS form and had become a major source of focus whilst I was writing the application. What was missing in the meeting was an opportunity to talk about benefits, relationships, opportunities and fun. Nind, summarizing Zeni, states that "engaged nature of action research" puts into focus ethical considerations such as "accountability, action for social justice...caring and respect" (29), which became priorities in my own study. I felt that I was presenting a deficit model of the research in not being able to fully articulate what people might enjoy. There is a thread of concern in the literature on what writers have called the “de-emphasis on benefits” (McDonald and Kidney 27), and support for “indirect benefits that may be particularly
important to people with learning disabilities” that could, for example, include a positive change to their normal daily activities.

There were only 6 questions asked, and after 15 minutes we were invited to leave. The pace and duration of the meeting left me a little stunned but I had the strong impression that the approval would be given based on two small changes: the addition of information on the Information and Consent forms to indicate my status as a PhD student, and to change the yes/no boxes on the Participant Information sheet to circles. I was very glad that I could discuss this impression with my supervisor who was able to confirm the small changes I was being asked to make, and how smoothly it seemed to have gone. Later it struck me how tangible the power structure had been in the room: there was a clear hierarchy and I was left with the impression that I was close to the bottom. This had been exacerbated by the lack of a summary or indication of where my project now stood, as I only left with the information that I would hear back from the REC within 10 days.

My supervisor's notes were helpful but she gave me one particular piece of verbal feedback, which was 'you are very good at translating what is in writing into spoken (messages) for your audience.' I am not sure anyone has actually said this to me before, but it was a reassuring comment - clarity is critical in helping others to understand research from a different discipline. Inclusive research is aiming to address traditional relationships and the generation and ownership of knowledge (Stalker 5; Iacono 177) and this has resulted in new ways of thinking about research design. Yet the inclusive research paradigm is still emerging (Stalker 5-6) and finding ways to express its aspirations. I have found the literature on this useful and refreshingly honest in its pinpointing of the "ongoing scrutiny" (Nind 31) needed of inclusive approaches and have seen in this an opportunity to develop a reflexive and critical approach in my own research practice.

The conversations after any important meeting are inevitably colourful: informed by reflection and focused on outcomes. It was now early evening and ours took place in a busy local pub. We were surprised at the speed at which the meeting had been completed and the lack of the traditional formalities such as introductions. We reflected on the focus of questions. It was clear that the line of questioning had only offered me a small window of opportunity to talk about one of the creative elements of the project - the art-making space. The rich details of other parts of the project such the approaches to participatory
video-making, were not discussed. Thus an opportunity to consider the broader relationship participatory arts had to situated ethics was missed. The participatory arts opens up a space for people with learning disabilities to participate in self-representation and self-advocacy; they involve people with learning disabilities "in the process of doing the research" (Walmsley and Johnson 64). They also provide a platform for people to tell a story from their perspective, thereby mobilising a mechanism that gives audiences the opportunity to develop an understanding of "the experiences of others" (Goodley and Moore 49). In doing so they meet with a key principle of inclusive research "that it must access and represent...views and opinions (of people with learning disabilities)" (Walmsley and Johnson 16). In their discussion of research that includes people with learning disabilities and the arts, Goodley and Moore summarise this position:

The extent to which disabled people and their allies have an opportunity to have their say, be listened to and have their views taken seriously within the research process is now regarded as probably the most important indicator of the validity of any piece of disability-related research. (23)

Yet the nature of working with inclusive methodologies presents "extreme challenges" (Nind What is inclusive research? 30) and means that research is sometimes difficult to pin down. As it currently stands the practical framework for NHS ethical approval as realised in the IRAS form echoes of a particular model of research, and in doing so raises the question of whether it is fit for purpose elsewhere. Although it includes an opportunity to express some of the activities participants will be engaged in, it does this in a way that suggests research is something that is 'done to' and always pre-planned rather than 'done alongside' or 'done for' with the detail of activities emerging in real time, as with participatory action research. This is particularly true of IRAS form question A.18 where the researcher is obliged to present a series of activities in a table, completing columns about the amount of time an activity will take and how often the participants will undergo the activity. The researcher is asked to "give details of all non-clinical intervention(s) and procedure(s) that will be received by participants as part of the research protocol" (8). My italics). All this suggests a certain hierarchy in terms of the roles of researcher and participant, and a particular research culture where participants are passive recipients. This seems at odds with research approaches where in all reality full answers to such questions may emerge.
The post-REC period was frustrating and at times, confusing. There were two administrative delays and what seemed to be an avoidable error that caused me some real concerns. I had two further iterations of the Information and Consent forms to make and was informed of what was required in these via letters from different sub-committees. The main thrust of these changes was around further articulation of potential risk to the participant, anonymity, withdrawal from the project, and the management of data should a person decide to leave. The forms, particularly for participants with PMLD, had I felt, become unwieldy, now containing long sections of text. The impression I got from the NHS sub-committees' directives is that they were approving the final shape of the forms they wanted me to use, yet the versions I was left with would be mostly unusable in the field. After making the required changes and a period of chasing the administrators at my REC office, I received a final decision letter on a Friday afternoon. Much to my confusion and apprehension, it seemed to contradict itself. It said both that the project had been granted approval but that it did not meet its legal requirements, stating "the Committee did not approve this research project for the purposes of the Mental Capacity Act 2005. The research may not be carried out on, or in relation to, a person who lacks capacity to consent to taking part in the project" (QueenSquare REC, personal correspondence, 2014).

This was a low point for me. I knew that the ethical approval and legal compliance journey was tough going, but at times it felt like getting on a roller coaster. It seemed a long way off before I could arrive at the part of the project where I could start the business of working with participants and collecting data. I contacted my supervisors over the next day or two and discussed possible strategies to address the matter. I was concerned by the letter and the seemingly contradictory information in it. A weekend can feel like a long time when it appears that a project has hit a brick wall, but the nature of working in the participatory arts had prepared me for the unexpected. On the sensible advice from my supervisors, I put the letter aside for the weekend and an enquiring phone call to the REC administrator early that following week resulted in the realisation that I had received the wrong version of my letter. The administrator had been busy and had mistakenly left in the paragraph that had caused the confusion. Although my application had gained approval after all, the impact of this clumsy administration had been a period of anxiety and a sense of the scale of the task ahead of me if I was required to make substantial changes to the application. Aman and Handen talk of the "extreme administrative constipation" characteristic of the ethics
application process that they have faced as researchers (180); elsewhere it is described as an 'administrative burden" (Iacono 175) My lead supervisor had provided a positive spin though, reminding me that I would have interesting research stories to tell later on.

I have wondered throughout this process why the same sub-committee members were not steering the required changes. My impression was that increased transparency would be beneficial in matters that could delay and otherwise negatively impact projects. Either way I wanted to identify what had shaped some of the concerns. The initial sub-committee had asked me to focus on and highlight the potential risks to participants with PMLD and to clarify how their anonymity would be protected. My impression was that they were incredibly risk-averse, and it surprised me that they did not take the opportunity to discuss concerns with me more during the very short (15 minute) meeting. Aman and Handen reflect on the case of the US, describing the "tendency towards increased regulation (by the national ethical approval body as) a climate of fear". They suggest that there is a "hierarchy of protection of (a) self (b) the institution, (c) the participant, (d) the investigator" (180) with (a) describing the ethical approval body.

Very shortly after NHS ethical approval had been granted, there were additional pressing but conflicting demands on the ethics of this project. I had requested ethical clarification from the day centre where I would be delivering the practice-led part of the project. Specifically I had wanted to ensure that any processes Portsmouth City Council (PCC) might wish to have in place were completed ahead of the start of the workshops. A week prior to the planned recruitment procedure, I received an email asking me to complete some paperwork ahead of a meeting at PCC. This was completely unexpected but the process presented few real problems beyond clarifying attached comments from the PCC Governance Manager. However, I was concerned about how little understanding there seemed to be of the project, its aims and approach. In her initial email to one of the day centre Managers, the PCC Governance Manager said "I did feel slightly curious where the researcher asked for our staff to observe the film at the end of day to help decide if people had a reaction to different elements of the test" (Email correspondence, April 2014, my italics). The problem was clear: contact between the PCC Governance Manager and the project was being bridged by someone other than myself, and that meant there was an opportunity for miscommunication. There was now a bank holiday weekend bookended on one side of the meeting in which the paperwork would be reviewed by PCC at their
meeting, and on the other by the recruitment process consisting of capacity assessments and best interest meetings. I had a growing concern that the project would drift as it involved a number of stakeholders and had required a good deal of organising diaries and timetables in order to get the recruitment meetings planned. Despite my understanding that I would be told the outcome of the meeting prior to the weekend, I heard nothing. I made the decision that recruitment plans would need to be cancelled and remade.

In considering the relationships between researcher and participants, Nind and Vinha (2013) pinpoint the critical nature of establishing trust and rapport. In my experience this extends to partnerships where open discussions can take place, and institutional and project concerns be addressed. I reflected that the delay could have been avoided if an offer I had previously made to meet with PCC colleagues and discuss the project further had been taken up. When I finally did receive a response from PCC it was via email, informing me that my recruitment process was "too complex for this client group" (Email correspondence, April 17th 2014). I was directed to change my consent process by abandoning the forms I had designed. Instead I was instructed to devise one simple form that could be signed off by family members. This would negate the need for the recruitment procedures and instead provide me with a “simple” solution (Email correspondence, April 17th 2014). However, at first glance, these suggestions seemed to contradict both the guidelines of the Mental Capacity Act 2005 (Code of Practice) and the input of the NHS ethics approving panel. It was clear that I would need to address the ethical issues that would arise were I to ignore legal and ethical directives.

In aiming to build better research relationships, I was keen to work closely with gatekeepers and this meant striving to open up a space for dialogue. I emailed my contact back, offering to meet with the team who were assessing the project but was informed that the Caldicott Guardian would most likely not be able to meet me due to her schedule. This was a disappointing response but Nind and Vinha state that "each new research project brings challenges in terms of breaking down barriers to participation" (7) and I decided that I would try to go around this particular wall. I requested a telephone meeting, which was granted. Meanwhile the project remained on hold. The 45-minute telephone meeting was challenging and I was presented with a number of perceptions that I had not anticipated; at times there was a real sense of protectionism. The key issues that emerged were around capacity, consent and attached to this, terminology and fear. There was already, I was
told, an agreed mechanism for capacity to consent at day services, with family members having completed paperwork to give best interest decisions for the activities a person might engage in. I would not need to conduct my own capacity assessments for this study. I reassured my contact that I had followed the MCA’s guidelines and NHS ethical requirements and would be conducting the capacity assessments with colleagues from the NHS and PCC Day Services - the final decision would not lie with me. This was the position that had gained the project NHS ethics approval. My reminder that I would need to comply with the law was met with the sharp retort that the suggestion PCC were not MCA compliant would not be tolerated. My contact said "I am not having you saying that". Yet the MCA Code of Practice states, “a person’s capacity must be assessed specifically in terms of their capacity to make a particular decision at the time it needs to be made” (2007, p.40, my italics). Capacity assessments are critical in ensuring that a person has access to “all the possible steps to help (them) make a decision for themselves” (2007, p.40). The Act further emphasises independence of decisions wherever possible by telling its users that their starting point should be, “always to assume that a person has the capacity to make a specific decision” (41). In short, the Act is very clear that “capacity should always be reviewed….as particular decisions need to be made” (50. My italics).

I have discovered that, among other skills, working inclusively requires diplomacy, tact and often courage. In order to enable this democratisation, the researcher has to pass through the processes and procedures of gatekeepers, who may not be aware of, or share these ambitions. There may be negative or fearful perceptions of research and these may be linked to institutional criticisms outside of the experience of the researcher, as later emerged in the case of this study. Nind, in discussing research with children, highlights parallels I have recognised in attempting to work with PMLD populations, when she reminds the reader of the “challenges associated with gatekeepers and overprotection” (What is Inclusive Research? 29). I reframed my earlier MCA comment whilst assuring my contact that I was not accusing PCC of anything, rather attempting to clarify my position within the framework of the law. The conversation moved on. The rationale for the new best interest process was that it would be "much less frightening" for family members as the terminology in my current forms would be "beyond their experience" (Telephone conversation, April 2014). My contact suggested I use layman's terms such as, "I want to do this piece of work" and "can you decide as a family if you are happy for your person to participate", and in giving consent, "I have no objections for X to take part in the research"
(Telephone conversation, April 2014). I recounted that I had previous research experience where families were well versed in NHS 'speak.' I also outlined that ways in which myself and colleagues at day services were planning to support families to attend best interest meetings where the original forms would be discussed. I clarified that a best interest decision were it needed, would be informed by a range of people in line with previous research working with the NHS services in the city. I was told that just because people were "familiar with NHS speak, it doesn't mean that we wanted to expose them to more" (Telephone conversation, April 2014).

Despite the challenges, I was determined to stay with the conversation until it took a more positive turn, and to stand my ground in terms of the ethically agreed processes already in place. It ended strongly, my contact acknowledging the work I had put into the project and the juggling act that constituted meeting the requirements of different stakeholders. When I later received communication on the reconsideration of the project, the outcome was based on the understanding that had been reached in this pivotal conversation. I was to be allowed to continue using my proforma and was asked, in addition, to devise a simple introductory letter about the project to family members. In ongoing discussions with colleagues and project advisors I began to learn that the Council was facing institutional criticisms that formed a backdrop to the conversations I had been involved in. It was likely that this had at least some degree of influence on the positive and negative positions of staff members in terms of my research study. It might be that this had muddied the waters when I put forward my initial NHS approved processes. A deeper awareness of relevant institutional pressures faced by the Council might have helped me to better articulate my study in this early phase. Some fact-finding at the start of the project supported with well-phrased questions and face-to-face meetings may have curtailed some of the delays I experienced later.

My journey towards ethical approval has been about finding a balance between the requirements of the NHS Ethics Committee, the processes of Portsmouth City Council, and the principles of inclusive research. The sub-committees who looked at my IRAS form were made up of medics, psychologists, neurosurgeons and statisticians, but there was no representation by artists, care staff, or others working in settings related to the study. If there had been, I would have perceived it as a more inclusive approach to the reading of the project. The ethical application process is extremely demanding not just as an
administrative burden but also as an exercise in articulating a project to those who are familiar with different research cultures and characteristics. My supervisor and I had left the REC meeting feeling that the application had been successful except for a few minor tweaks. There was a mismatch though compared with the level of detail in the changes I was subsequently asked to make. I had wondered about the mechanisms for reflecting back to applicants at the end of these meetings. I felt that I was not party to preferred or established ways of conveying information within IRAS applications and although I was happy to learn on the job, I could be penalised for such a lack of insight. I was very aware that my inability to gain ethical approval would result in potential participants being denied access to involvement in research that was about them.

Despite the guidance notes given to those applying to RECs, I thought at times that I was at the whim of the particular preferences and expectations of committee members. There seemed to be a good case for more assistance for researchers undertaking this process from fields outside of medicine and science; clarity and direction are more slippery when studies progress to sub-committees. This is because sub-members will not have attended the original panel meeting, and have not had a chance to meet the researcher or vice versa. In her experiences with RECs in Australia, Iacono reflects these concerns, noting the burden she faced in meeting the particular and often differing requests made by those commenting on her application (174-175). Participatory arts is an area where research practices are emerging, as is knowledge on including people with PMLD in research. In the UK the journey to be made in the attempt to engage with NHS ethical approval with projects that present creative research methods, poses a range of challenges and opportunities for researchers.
Chapter 5

Data-collection and Analysis

Multiple data sets were collected for this doctoral study; the diversity of data forms gathered allowed for exploration from multiple perspectives and via a variety of investigatory styles. Over 200 hours of film data were captured: a filmmaker was engaged to work to a weekly film script but other than this filming was unplanned or intuitive. Data were not always complete or usable. Some of the Go Pro footage was lost when cameras were moved by those wearing them; a slipped camera meant extended footage of the desk or ceiling. The Dictaphone did not always provide consistent and reliable data when it was placed too far away from the person being recorded, or when the room was particularly noisy. Despite the limitations of some of the chosen data collection methods, they contained a political commitment seen within participatory arts practices that aim to be “constructive and ameliorative” (Bishop “The Social Turn” 11) and to “overthrow…a previously stable or at least dominant order of ways of knowing” (Schostak and Schostak 1). Through these data there was cogency in the overall picture that emerged in each case.

Table 1 Scope of the Dataset

<table>
<thead>
<tr>
<th>Type</th>
<th>Quantity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Artworks</td>
<td>100</td>
</tr>
<tr>
<td>Artwork Photo Archive</td>
<td>1,000</td>
</tr>
<tr>
<td>Workshop Photo Archive</td>
<td>2,000</td>
</tr>
<tr>
<td>Data Triangulation Sessions - Film</td>
<td>8 hrs</td>
</tr>
<tr>
<td>Workshops – HD &amp; iPad Film (Film maker)</td>
<td>120 hrs</td>
</tr>
<tr>
<td>Workshops – HD Camera (Hayley)</td>
<td>30 hrs</td>
</tr>
<tr>
<td>Workshops – Go Pro Cameras</td>
<td>50 hrs</td>
</tr>
<tr>
<td>Audio Data - Dictaphone</td>
<td>20 hours</td>
</tr>
<tr>
<td>Post Workshop Questionnaires</td>
<td>140</td>
</tr>
<tr>
<td>Capacity and Consent Forms</td>
<td>14</td>
</tr>
<tr>
<td>Reflexive Journal</td>
<td>20K words</td>
</tr>
<tr>
<td>Micro Analysis Notebooks</td>
<td>4</td>
</tr>
<tr>
<td>Person</td>
<td>Role</td>
</tr>
<tr>
<td>----------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Josh</td>
<td>Learning disabled participant; each participant presented on a spectrum of abilities against the working definition of PMLD as outlined in this thesis. Each participant engaged with creative materials and tools in a range of ways as outlined in the analysis of individual case studies, and demonstrated through Process Films and the Photo Thesis. These included wearing Go Pro cameras, using hand held cameras and engaging with paint, charcoal and plant materials.</td>
</tr>
<tr>
<td>Hayley</td>
<td></td>
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<tr>
<td>Katherine</td>
<td></td>
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<tr>
<td>Charlotte</td>
<td></td>
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<tr>
<td>Rob</td>
<td></td>
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<tr>
<td>Sharon</td>
<td></td>
</tr>
<tr>
<td>Dani</td>
<td></td>
</tr>
<tr>
<td>Mark</td>
<td>Care staff participant. Each carer undertook a complex role that required them to work with learning disabled participants in their professional capacity using participatory arts methods, and to act as part of the research team by contributing to theory building. In this latter role staff completed a weekly written evaluation form to articulate details around activities and processes; they also participated in video data triangulation meetings. In addition they engaged in ongoing dialogues that enabled me to prepare, anticipate, and reflect on participant progress. All care staff participants received ongoing in-workshop training as part of a continuous model of reciprocal learning and skills sharing.</td>
</tr>
<tr>
<td>Chrissy</td>
<td></td>
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<tr>
<td>Aby</td>
<td></td>
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<tr>
<td>Julie</td>
<td></td>
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<tr>
<td>Jayne</td>
<td></td>
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<tr>
<td>Steve</td>
<td></td>
</tr>
<tr>
<td>Bree</td>
<td></td>
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<tr>
<td>Kelly</td>
<td></td>
</tr>
<tr>
<td>Harriet</td>
<td>Additional care staff participants who joined the project later on. These undertook the additional training I developed in response to consistency issues in staffing cover.</td>
</tr>
<tr>
<td>Hannah</td>
<td></td>
</tr>
<tr>
<td>Janice</td>
<td></td>
</tr>
<tr>
<td>Jackie</td>
<td></td>
</tr>
<tr>
<td>Philip</td>
<td>Day Centre Manager. Key stakeholder and gatekeeper; Philip approved the go-ahead for the workshops on the premises, agree allocation of a room and storage space, and gave me permission to work with care staff and the Assistant Manager.</td>
</tr>
<tr>
<td>Janice</td>
<td>Day Centre Assistant Manager. Key stakeholder and point of contact; Janice liaised with me by email and in person to discuss staffing allocations and to nominate a member of staff who would support the administrative functions of the recruitment drive. She advocated for the research with parents and key supporters and helped me to organise a coffee morning for them so that they could learn how the workshops were progressing. Janice acted as the Decision Maker for the Best Interest interviews.</td>
</tr>
<tr>
<td>Jo</td>
<td>Senior Occupational Therapist for the Kestrel Centre and advisor on the recruitment processes. Jo shared her expertise and knowledge of NHS / Mental Capacity Act compliant processes for establishing Capacity and gaining Best Interest permissions. Part of this sharing included supplying tried and tested pro forma that could be adapted for the study, collaborating on room set up for Capacity and Best Interest meetings, advising on the conduct of such meetings and acting as a critical friend on my paperwork for these. In addition Jo co-signed the assessment of Capacity forms.</td>
</tr>
<tr>
<td>Eve</td>
<td>Filming Support. Eve worked to a different film script that I had written prior to each workshop in order to capture specified data; she prepared the cameras and memory cards. Eve developed a reflection of workshops in the form of a drawing and attached notes. We engaged in brief regular post-session conversations to identify key MAs and any issues or barriers.</td>
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</table>
Data Analysis Strategy

This study is situated in a methodological framework that calls attention to the "democratic, ethical" (Finley 435) and active participation of people with learning disabilities (Chappell 38). Foci of interest including collaborative activity, contextual influences, choice-making and the acquisition of new skills in utilising materials and tools, the role of relationships, and the emerging art-making processes. The inclusion of research methods that enabled participants to self-record their experiences attempted to address the traditional privileging of the researcher as specialist (Chappell 40). This project used a mixture of manual and software analysis approaches in order to best interrogate the particular mix of data collected. Analysis was perceived as coming to an understanding of practice as produced by a “particular set of intentions, conditions and circumstances” (Kemmis and McTaggart, 279). Data analysis occurred across 5 discrete, sometimes iterative stages: data triangulation sessions with day centre staff; manual coding of visual data using notebooks; management and coding of photographic archive; data structuring and reduction using Premier Pro CC editing software and data networking using Atlas.ti qualitative data analysis software.

Data Triangulation Sessions

Here preliminary data analysis was treated as an ongoing activity (Coffey and Atkinson 6; Gray and Malins 4) undertaken at weekly stages after each workshop. This initial review was where cataloguing of the "activities and events that have been recorded" (Heath et al. 62) could occur. Heath’s description was utilised to support the development of emerging themes and categories for the data. Among the factors of influence were the range and complexity of communication strategies used by participants (Chappell 41; Stalker 6; Ware 176), some of which were unknown or unreliable at the start of the project. The analysis of visual data was undertaken with strong reference to its participatory nature (Coffey and Atkinson 14-15) and so, as discussed, a further analytical approach was to test initial assumptions through discussion with day centre staff in regular data review sessions (Heath et al. 65). These occurred every four weeks in an hour and a half long sessions, resulting in a total of five sessions across the study.
The framework for the data review sessions accounted for ethical, practical and institutional factors. In order to avoid coercion and to provide a range of perspectives, a changing selection consisted of staff members self-nominated from a group of those who signed up to participate in the project. This was supported by a drop-in arrangement that enabled staff to attend around their work commitments thereby maximising the time available to both researcher and staff. Staff numbers were kept small relative to the thirteen people who consented to participate in the project. Alongside this drop-in arrangement, and in order to improve transparency and support a broader institutional "buy-in" (Wenger et al. 102), there was be an open door policy at the set up and end of sessions. This is where other staff not involved in the study could observe artifacts, ask questions, and exchange in dialogue (Coffey and Atkinson 154). Data review sessions were located at the New Road day centre and, in order to take account of resource limitations, needed to be held in "improvised screening rooms" (Mitchell et al., 180). They included analysis of individual video clips kept to a manageable duration of up to one minute; these were shown both in isolation (Heath et al. 2010) and sequentially. There were a number of contributing factors in the decision to sometimes show sequential video clips rather than the isolated 30 second clips recommended by Heath et al. (2010), based on my experience in the field and on the interdisciplinary literature. In the interactions of the complex 'messy' setting of the day centre dining room (Mansell and Beadle-Brown, 12), participants become distracted or interested in other activities or items; people other than those participating in the study moved in and out of the space, sometimes wishing to observe the activities of participants and their supporters. GoPro cameras slipped in their harnesses and toilet and other breaks were required. These factors created a 'stop-start' rhythm in the footage meaning that observers needed to view a number of clips to comprehend the fullness of an action, process and interaction.

Although Heath et al. (65) outline best practices approaches to conducting data sessions as discussed above, they do not provide details on the filming of data sessions. Attending to Mansell's and Beadle-Brown's description of social care and its institutions as a "complex world.....where many different factors work together to influence the outcome" (12), meant that due care needed to be taken to understand the "causal pathways and processes involved in....and the real results of particular courses of actions" (Mansell and Beadle-Brown 12). In order to facilitate this, I gave particular consideration to how myself and care staff might "support or inhibit participation, expression and agency" among
participants (Mitchell et al., 182). I employed a colleague to undertake some filming in the workshops to enable me to step back and observe the setting more often than I otherwise would have been able to do.

Data triangulation sessions were perceived as opportunities to develop insights and maintain the rigour of the research methodology. As Mansell and Beadle-Brown remind researchers, it is "easy to deceive ourselves about what is going on when introducing innovations in practice" (12). Outcomes of reviews included the confirmation, denial and clarification of the meaning and function of participants' verbal and non-verbal messages. Agreed examples of assent and dissent were established as ongoing and practical examples of situated ethics (Ramcharan and Cutcliffe 363-364; Dye et al., 147-148). In addition, data supported critical discussions about the inclusive arts approaches being developed and how new ideas can be developed and tested. These comments acted as verbal annotations and in the Atlas.ti software, relevant film stills were collated alongside verbal tags to create another layer of data analysis, taking the form of a visual log. Triangulation of video data enabled agreement to be reached on what might constitute ME. An overarching concern was in identifying how the structural elements of the workshop might support participants to experience them as inclusive. Inclusive research methods support an emerging, exploratory approach as reflected by Nind, and "academics sometimes need to launch a project and allow this organic development for participation to grow" (56).

**Manual Coding of Video Data using Notebooks**

Coding was conceived as an analytical strategy that included three steps. Firstly I observed relevant phenomena as those that emerged consistently or as notable exceptions, then I moved through to the collation phase that pulled together linked examples into sets or categories satelliting around critical commonalities such as an action or idea. The last stage of analysis was where coding was employed as a "heuristic device" (Coffey and Atkinson 29) cast as a bridge between the data and the developing research theories. The initial manual examination of the data was conducted as a micro-level sweep of video data with my observations recorded manually in a series of notebooks; here inductive codes were noted. Whilst initial possible codes were identified through the
literature review, the approach for inductive code development was weighted more significantly. Raw codes were allowed to emerge from the data and these were captured in my notebooks alongside in-the-moment reflective commentary on elements of the practice and some early theory building.

Early theory building began to be observable from Week 7 as seen from the notebooks plainly evidencing the time needed for me to sensitise to the research context. The scale, scope and pace of theory building grew from this point in and some assumptions characteristic to the practice and context began to emerge; at other times theory was focused on material and materiality and was participant-specific. In terms of scope, the notebooks also facilitated a view that went “beyond the data” (Gray and Malins 135) drawing together ideas that might become more broadly transferable to practice such as principles for researchers working in similar contexts. These principles eventually coalesced into a set that would speak to the conditions for ME also observed in this study. Whatever the focus of the theory-building, it documented the syntheses made between data, reflections and research questions and evidenced the cyclic, layered and methodical approach that I brought to the analysis. This commitment to accountability in qualitative research has been underscored elsewhere (Walmsley and Johnson 176-180) and characterised as a necessary clear-cut “chain of evidence” (Gray and Malins 133).

The notebooks I developed were a form of manual record and represented a dynamic, developing site for focused examination of the video data to occur alongside my experiences and thinking processes. The notebooks included the adoption of visual devices that enabled the initial ordering and assessment of data including colour-coding for categorisation and boundarying of chunks of emerging theory. Highlighting, underlining and comments were also used as visual devices (Gray and Malins 5-8). The notebooks represent early, natural internal conversations with the study "when thoughts are racing as the emergent ideas and concepts are beginning to take shape, but have not yet crystallised" (Butler-Kisber and Poldma 9). They located the emerging theories against the data and reflections that provoked them, providing a concrete record of analytical evidence. These conversations also happened across the book clearly evidencing development of ideas as the study continued; periods of critical thinking were seen in the occasional dense pockets of writing. The notebooks provided a useful, portable site for thinking through and revisiting the data, and although intensely time-consuming to
populate, proved to be a thorough record during my many revisits of them as the study progressed. They enabled me to develop a better understanding of, and subsequent relationship with, the participants and their care staff.

Care staff relationships are critical to the success of creative working with people with PMLD (Mencap.org.uk) and are expressly aligned with the research objectives for this study. Mansell and Beadle-Brown, through an analysis of research from the USA, evince this position: “engagement in meaningful activity could be promoted by changing the way … staff provided support for the people” (17). This was particularly important in this study where there would be an emphasis on what might sometimes be subtle participant-specific communicative features such as non-verbal cues, assent and dissent positions, objects of reference and vocalisations. At this stage of analysis, codes were attached to these communicative features as I observed them through the film data. Gray and Malins’ discussion of a definition of analysis as outlined by Bunnell, regard it as “three concurrent flows of activity – data reduction, data display and conclusion drawing” (141). The use of manually completed notebooks allowed me to make the best of the "messy" (Butler-Kisber and Poldma 5) thinking processes that occurred at this stage in the project where reflection, analysis and theory often intersected.

Management and Coding of Photographic Archive

The project amassed a large number of photographs of developing art-making processes and final pieces of artwork. These were stored weekly on an external hard drive in participant-specific folders. Photographs that seemed to uphold or embody the skills leading to moments of Meaningful Activity (MA) such as the development of a creative process via the use of a new tool, or a more confident approach to making were individually annotated in Preview for the Mac and exported back into the eternal hard drive, again within participant-specific folders. Annotations were made as listed words or phrases that allowed exploration rather than reduction. The objective was that this would enable unplanned combinations at both case and cross-case levels to be made, particularly when the images were moved to Atlas.ti.
Initial structuring of the video data occurred through its reduction via the Premier Pro CC software; this required a second sweep of the data enabling me to gain further sensitisation to them. At this stage I was looking for evidence of MA but within an extended chronology, in order to situate these key moments within the broader context of the workshops. In this way I began to understand the “framework for the phenomena” (Lopez 14) and through this, the conditions that might constitute ME. In order to manage the analysis, data were contained within the same time-bound border of up to 4 minutes either side of the MA. This was decided upon at the previous stage of analysis where it was deemed suitable for both locating relevant contextual factors and, in part, representing the variable pace at which MAs might be arrived at. MAs were then filed in individual folders and attached to other data that seemed to be supporting the development of ME as well as similarly reduced data from dictaphone recordings and triangulation sessions. The software was limited to the types of data it could reduce and so photographs, questionnaires and my reflexive journal were managed at this stage of the strategy, only in terms of their categorisation into MA folders.

In this phase of the strategy I was analysing sections of film data that ranged from 10 seconds to 30 minutes long. Premier Pro CC aided data management in that I could drop data from across a number of workshops into the software, which contained differing degrees of detail; this allowed for contextual granularity to emerge (Coffey and Atkinson, Chapter 2). Some of the data were unusable; my exclusion criteria included sound and visual distortions such as unwanted voiceovers, focus and compositional errors and footage where people who were not participating in the study had wandered into shot. All or any elements that rendered data spoiled or unusable for the study were deciding factors for their exclusion. Inclusion criteria for data were that an MA was present; other data considered critical for inclusion were those that illustrated perceived contextual and human barriers to ME occurring, or which seemed to support ME. The software enabled precise editing cuts to be made to data and for clips to be organised and easily exported in a range of formats. This allowed me to share data with my supervisory team and day services staff in secure, password protected locations such as Vimeo and via standalone hard drives.
Although clips could not be coded, the software enabled them to be organised in folders and files making for effective isolation of and access to the critical MAs.

Data Investigation using Atlas.ti Qualitative Data Analysis Software

The final stage of enquiry was facilitated through Atlas.ti qualitative data analysis software; this allowed for increasingly complex investigations to be run in relation to the research questions. Atlas.ti allowed the inputting and structuring of usable data via unique project areas and was able to manage all the data types that were collected in the project. It was at this stage of the strategy that the weekly questionnaires completed by day centre staff, my reflexive journal and consent and best interest forms, were coded and subsequently included for analysis. In order to progress through the software, research questions were systematically dismantled through the memo facility in order to design steps for progression; initially questions were case specific and sustained, enabling an intense analysis to develop.

Within the software I created process memos that outlined the journey of the study in terms of the ways in which questions were approached and as a method for “recording significant changes in direction” (Silver and Lewins 238). The use of memos led to a clearer understanding of which data needed inputting thereby avoiding unnecessary congestion in the analytical chain.

The actions of coding, cutting and subsequently pasting video and other data together into Atlas.ti as a response to lines of enquiry enabled me to perceive the act of coding as one that supported “the recontextualisation of data” (Coffey and Atkinson 31). In its new form, the data had been both clarified, and through its interaction with further lines of enquiry, complicated. Codes were further organised in Atlas.ti through the creation of thematic folders that enabled manageable levels of granularity and clarity to be achieved for the data. The data analysis strategy discussed enabled me to look at cases individually by categorising primary patterns in the data and agreeing these as significant through triangulation with staff and key supporters. The approach discussed above provided validity of the individual understandings of the cases through prolonged engagement with participants in the workshops and subsequent persistent observations of the data.

Narratives developed for each case in terms of participant ME and MA were established
through Denzin’s categories for thick description, which included biographical, historical, situational, relational and interactional details (Denzin Chapter 3)
Chapter 6
Case Studies - Governance of Data-collection Phase

The data-collection phase of this doctoral thesis took place weekly in Portsmouth involving a long commute from Cardiff the evening before each workshop. Workshops began at 10 am with my arrival at day services at 8.30 am to set up. This involved reorganising the dining room space into individual workspaces, carrying arts materials in from my car and moving all of the A2 participant work folders from their attic storage space down to the lower ground. Staff and participants started arriving from 9 am onwards and congregated either in the TV room or in the dining room; when new agency staff arrived I undertook mini sharing sessions with them and distributed Information and Consent Sheets. However, whilst essential in order to maintain ethical compliance, this activity effectively extended the duration of the workshops by thirty minutes to an hour. At 1 pm the set up process was undertaken in reverse before my drive back to Cardiff. There was often very little spare time in the pattern of delivery of the workshops: care staff had to resume their other duties for the day and participants got on with lunch, tea or another activity. Time was at a premium so effective governance was critical. Table 3 outlines the governance plans for the data-collection phase of this doctoral study. These formal arrangements were regularly supported through informal conversations and discussions on progress that took place between staff, managers and myself.

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Activity</th>
<th>Attendees</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>As and when needed</td>
<td>Mini sharing session with agency staff. 30 minutes.</td>
<td>New agency staff</td>
<td>Dining room</td>
</tr>
<tr>
<td>As and when needed</td>
<td>Check agency staff consent forms prior to session starting. 30 minutes.</td>
<td>New agency staff</td>
<td>Dining room</td>
</tr>
<tr>
<td>End of each workshop</td>
<td>Staff complete evaluation forms. 30 minutes.</td>
<td>All participating staff</td>
<td>Dining room</td>
</tr>
<tr>
<td>Every 4 weeks</td>
<td>Data triangulation. 1 hour.</td>
<td>All participating staff; Managers and Seniors</td>
<td>New Road</td>
</tr>
<tr>
<td>End of every workshop</td>
<td>Show and Tell. 20 minutes.</td>
<td>All participants</td>
<td>Dining room</td>
</tr>
<tr>
<td>Week 18</td>
<td>Coffee morning</td>
<td>Key supporters</td>
<td>Dining room</td>
</tr>
</tbody>
</table>
Case Study 1 – Kathryn

At the time of data-collection Kathryn had been attending day services in one-on-one sessions. Kathryn was put forward as a possible participant for the study who had a label of PMLD but was able to communicate verbally, reflecting the observation of Green et al., that there are often "large differences among the response repertoires" of people so labelled (32). During the capacity and consent process, it emerged that Kathryn used verbal communication to reliably communicate her assent and dissent positions using clear phrases like 'I am anxious'. Staff reported that Kathryn responded with anxiety to sudden noises and would move away and shout 'no' or 'stop'; they also reported that she learned best when in a familiar environment with familiar objects (Capacity and Consent Forms, 2014). Despite Kathryn being able to communicate verbally, her points of reference were difficult to interpret and I needed the support of her highly experienced support worker in this. In addition we were unable to identify her understanding about which activities she might undertake, the benefits of participating, or the full consequences of the research. These questions were part of our decision-making process in the assessment of capacity. Overall, we concluded that whilst we were confident that Kathryn could tell us if she assented or did not assent in the moment she was unable to demonstrate reliably that she could fully consent to participate in the study.

A barrier to Kathryn’s possible participation in the study was that she became anxious about unfamiliar noises, environments and people (Capacity Assessment, 2014). Given that I was inviting her to participate in workshops with an additional five participants, it was clear to me that there would need to be careful management of the workshop space and her interactions with others to support her to be in the setting. A further possible barrier to Kathryn’s engagement was a directive to the Centre Management team from home that she must not return with any art material on her hands and clothes. Although no reason was given, there was an implication from staff that this was not really justified in terms of her support needs, rather it was something they had to work around to ‘keep mum happy’. Later into the workshops when Kathryn had travelled some significant distance in her creative process, this directive would provide a useful touchstone. Kathryn’s progression and what I came to understand as her conditions for meaningful engagement (ME) are seen here through the lens of a Meaningful Activity (MA).
Meaningful Activity 1: Objects of confidence

Early into the workshops it became evident that Kathryn was developing a positive relationship with paint and paper and was confident in expressing preferences related to tools, location of her workspace and subject matter (Micro Analysis Notebook, Week 2). Whilst she had joined other service users in the dining area at lunch times and during tea breaks, sitting alone at a ‘quiet’ table supported her to be in the room. During Kathryn’s capacity to consent meeting, it emerged that staff had been working with her using the characters Spotty and Super Ted. This had taken the form of regular colouring-in exercises with felt pens and pencils and had established a consistent theme related to her creative activity. The literature reports on such objects being used in care settings with an emphasis on improving the communication and understanding of people with PMLD and recognises the dual commitments of time and staff capacity needed to implement their use (Simmons and Watson 35; Vlaskamp and Nakken 102). Although Kathryn articulated a preference via her regular requests for these objects of reference, her engagement with comics designed for a much younger audience could have readily been perceived as interaction with material that limited her creative potential, personal growth and content for future art-making (Photo Thesis).

Yet Kathryn’s capacity assessment meeting reflected the position of Day Centre staff that objects of reference would "support understanding" (Assessment of Capacity Form, 2014). I wanted to respond to the role of this reference material by asking questions about how it might be shaped within the period of data-collection in order to learn whether if, and in what form, it might contribute to ME. Across the first 6 workshops I organised, A4 colour printouts of Super Ted cartoon scenes were prepared as source material for Kathryn. I had learned from carers that Kathryn would ask for Super Ted and Spotty comics as a regular part of her interaction with them. By week 4, upon Kathryn entering the workshop space, she would ask for Spotty and upon receiving one of the handouts, take it to a table of her choice and place it down whilst she chose materials, tools and drank a cup of tea. Once tea was finished Kathryn would begin to paint. This often signaled the start of a conversation or narrative and I quickly began to perceive the printouts as providing a focal point of sorts: the characters were frequently referenced, often making appearances in Kathryn's stories and sometimes seemingly as lenses through which to tell of her own
experiences. In order to capture these references I began to record the narratives using a Dictaphone:

C – Carol
K - Kathryn

1

C: Hayley is filming Katherine’s painting
K: Oh dear. Spotty run for it!
C: What did he run for?
K: Drink of water. No! Ran the cup! Yeah he ran.

(Hayley departs and returns a few minutes later)
K: Quick run! He’s back again he is! Spotty quick run!

(Hayley departs again with her camera)
K: (giggles) He running didn’t he? Just running…(heavy panting) bit dizzy, dizzy, dizzy…
C: Are you running too?
K: Fast, stop, stop. Slow down! Stoooop! He pushed your chair faster did he!
C: Where’s he trying to get to?
K: Toys R Us
C: What’s he gonna get in Toys R Us?
K: Present. I don’t know. Party!

2

K: Spotty play keyboard
C: Are you doing your keyboard next?
K: Yeah…I’ll play it later

(Dictaphone Data, Week 6; Reflexive Journal, Weeks 2 and 6; Staff Evaluation Week 2)

It also appeared that Kathryn was leaning on the Super Ted characters to vocalise her anxieties around being in the workshops, particularly when unexpected noises and events occurred:
A service user not involved in the study comes nearer Kathryn’s table. He has been shouting in the dining room this morning)

K - If it’s noisy it’s alright I will talk to Spotty

(He comes closer)

K - (shouts) He’s barking at me!

C - Remember what I said. He just wants to know who he is working with.

K - See she’s all right, he just shouted at her that’s all. You never shout. Spotty’s not angry, not scream she’s just a bit worried that’s all.

K - She just shouts wants a cup of tea that’s the problem

C - Never mind; it doesn’t matter

K - Things do happen it’s not a big deal

C - I know it’s not; it’s over now

K – Yeah (giggles). Spotty help him, caring him

(Micro Analysis Notebook, Week 6; Dictaphone Data, Week 6)

From week 3, as an attempt to begin to introduce a new object of reference, I began to support Kathryn to put on a painting shirt as part of her arrival routine; the bright red-checked shirt was visually discernible from those used by other participants (Jones et al., 2002) and it was emphasised that this was her shirt for ‘making art' thus the same shirt was used each week. I had hoped that the shirt would give Kathryn a sense of ownership to appreciate that these were her workshop sessions. She quickly became used to the new shirt, consistently consenting to wear it and beginning to verbally associate it with her painting activity, stating “Shirt first, then painting.” Despite this new element in Kathryn’s routine there was no change in her continuing to ask for Spotty upon her arrival. There was, however, a pivotal shift in emphasis that we had not seen previously and one that led to an MA in week 9. In week 6, my notes and staff comments showed that Kathryn’s focus of conversation was increasingly on herself: "K was narrating a story that emerged from her art-making, she was referring to herself saying ‘What's Kathryn up to? What's she up to?’ (Micro Analysis Notebook; Reflexive Journal). This marked the start of a 3-week period distinguished by further narratives where Kathryn referred to herself directly and moved the Spotty image out of sight (Photo thesis; Process film). During week 9 I noted that Kathryn had developed her communication in a new way through an expressed
appreciation at praise of her artwork, something that we had not been able to support her to do until then.

4

K - I want to go on the swings. Painting first.
K - Janice go on the swing in a minute. Painting first.
C - Painting first then exercise? Do you want this moved towards you?
K - Yeah. And the paper.
C - Paper's there
C - Which way do you want the picture up? That way...that way?
(K sees the Spotty picture on her desk near her canvas)
K - Oh no! Spotty is here
(K moves the picture to the adjacent desk where for the first time it is out of physical reach)
K - Ready
C - When you are [ready], go for it
K - Ready, steady, go!
C - Ready, steady. Go for it.
K - Marks, set, go!
(K begins to paint)

(Dictaphone Data, Week 6)

5

C - What do you want to do?
K - Paint on it
C - All your efforts. Ready, steady....
K - Yeah! (K emphatically painting)
C - Wooo! That's beautiful Kathryn.
K - Yes! Yes! Is!

(Dictaphone Data, Week 9)

Although Kathryn’s reliance on the Super Ted/Spotty characters continued, it did so at particular times, such as on her morning arrival at the workshops and at times of stress or
anxiety; a decrease in references to the characters was seen as Kathryn's painting process, confidence and material aptitude developed, alongside her social relationships (Dictaphone Data, Weeks 9, 11, 13 and 19; Photo thesis; Process film). The data showed that Kathryn was verbally associating her shirt with the activity of painting (Jones et al., 2002) by asking to put it on when she arrived at the workshops and to take it off when she had finished painting. This remained durable across the life of the study. In its role as a positive reinforcement of her regular activity, the shirt acted as a traditional object of reference. The data indicated that the second object being examined, the A4 printouts were treated differently because their emphasis had changed across the study. Kathryn came to prefer these as objects that provided consolation and comfort and as such, they no longer provided signposts to the practical framework of the workshops. Rather, they were sought out as a focal point to which she could safely direct her anxieties when workshops were underway and in order to highlight this critical difference in their utility, I constructed them as objects of confidence.

6

(One of the participants has been shouting)
K - Janice, David's angry
C - He is. He just wants to watch us do art. We are having so much fun he doesn't want to go.
K - It's ok. Don't panic. It's all right.
K - Super Ted doesn't like the noise. Super Ted has a headache.
C - Are you ok to stay here Kathryn? We can paint somewhere else if you want
(A long pause and then K picks up her brush)
K - No. She's ok. Spotty's laughing now

(Dictaphone Data, Week 11)

Meaningful Activity 2: I am an Artist!

Kathryn's developing process of painting: the development of gestures in terms of scale, confidence of line and colour mixing, and an increasing playfulness of approach are seen here through the lens of Maclagan’s definition of aesthetics. This he defines as "grounded in the material properties of painting rather than referring to some disembodied realm of
judgments about beauty and truth” (Maclagan 7). My reflexive journal noted Kathryn’s emerging process: “K’s painting process has developed in a number of ways that seem to demonstrate a relationship between the scale of the support, her choices of colour and her range of mark-making” (Week 16). The data shows Kathryn’s movement from paper to canvas, her utility of different tools and how these factors impacted the marks she made. Sometimes she chose to work paint into the canvas with a sponge or brush or scooped it onto her brush and layered it on top of already worked areas in thick, generous daubs (Photo thesis; Process film). Kathryn more commonly favoured a circular or semi-circular mark that varied in position and scale (Photo thesis; Process Film). I noted, “a single unhesitating but carefully made arc pressed hard into wet paint seemed to indicate a moment of particular focus” (Reflective Journal, Week 12).

Outside of this general pattern of development, the data from weeks 4, 10 and 16 illuminate a series of significant jumps in Kathryn’s creative choices, independence and willingness to engage in new experiences. These jumps are understood as a series of important MAs arrived at through Carol and myself supporting Kathryn to take risks at times that felt safe to her. When she seemed ready, we introduced canvas in place of paper, and sponges as well as brushes; I thought of this approach as safe risk. As these new material options had been adopted Kathryn had started to really settle into the space and became less anxious about the noises in the room: the canvases had seemed to support her to make larger, more playful marks, and she began to cover a bigger surface area before deciding paintings were ‘done!’. She had begun to work in a new, emphatic and confident way that was very playful (Photo thesis, Process film).

In week 4 Kathryn began to branch out beyond her reliance on green paint for the first time by independently choosing red when offered a range of colours, possibly enacting her increasing independence (Staff Evaluation, Week 4; Micro Analysis Notebook, Week 4; Reflexive Journal, Week 4). Carol reflected the effect that the addition of this new colour seemed to have on Kathryn’s confidence: “What was new today was that Kathryn had a different level of concentration because she painted for a longer time using the new paint and large paper” (Staff Evaluation, Week 4). In order to maintain the momentum Kathryn had established from choosing this new paint colour as described, I worked with her and support staff to further develop material competence through mixing her own colours. We worked on material skills: how to mix paint so that the colours combine together properly,
and knowledge: blue and yellow makes green, darker blue makes a different type of green. Using a large piece of card with three swatches painted onto it we developed a visual aide memoire for mixing green, resting this up against the workspace wall and encouraging reference to it each week as we practiced mixing.

During workshop 8, I had introduced Kathryn to canvas for the first time and although she had consented to touch it, she dissented to working with it over her usual paper; we continued to gently offer the canvas making sounds on its surface and sharing work that other participants had already created on canvas through our weekly show and tell. In week 10, Kathryn assented to begin working with it first through flat layers of red and then via concentric applications of her mixed green which she named ‘Kathryn’s green’ (Photograph 1 ‘Kathryn’s Green’). Carol noted these significant developments: “Kathryn was offered canvas to paint on today which enabled her to move her brush in different, bigger ways, because the canvas was bigger...what was meaningful was that Kathryn seemed to really enjoy the way she could work with canvas that the small pieces of paper didn’t support her to do. She was telling a story when she was painting a long brush stroke and said “The house was this big!” and “K chose to mix her colour, splatter it on the canvas with a really big brush she hadn't done before and to name it as well!” (Staff Evaluation, Week 10).

Kathryn’s developing process became increasingly characterised by her laughter and a willingness to use the paint freely; it was flung from the large artist’s brush she favoured and splattered, dripped and swirled on to the ever larger canvases with increasing quantities of water (Photo thesis; Process film). Carol and I began covering ourselves in spare painting shirts, encouraging new ways for Kathryn to experiment: “What will happen if you add more water to the paint?” whilst applauding her focused attempts to ‘get the splatters on the painting’. Scale played a key part in Kathryn’s art-making, indeed such was the physicality of her mark-making that she was able to work with canvases stacked side to side or in a ‘U’ as paint marks grew ever longer (Process film). I noted that her previous aversion to getting materials on her skin was not articulated at all in the last four workshops as she quietly transitioned to her post-session clean up without a mention of being ‘dirty’ (Micro Analysis Notebook, Weeks 17 – 20). Alongside these material changes, Kathryn began to overcome previous social anxieties in order to share her creative play and enthusiasm for painting with others. The leaps in process-development were
discussed above as a series of MAs at weeks 4, 10 and 16; these led to another pivotal MA moment in week 19 when Kathryn, now comfortable to have Hayley painting next to her, turned excitedly telling her, “You are an artist! I am artist!” (Staff Evaluation, Week 19, Dictaphone Data, Week 19).

**Meaningful Engagement**

Through the exploration of the data linked to this case study, I came to recognise the interplay between the social dynamics of the art workshops and the creative act. There were a number of sensory factors negatively impacting on Kathryn's ability to meaningfully engage in the workshops, to be able to relax and eventually undertake creative play. The data reveals these to be the vocalisations and proximity of other participants and physical contact with art tools and materials. In addition, Kathryn faced external pressures to keep her clothes and hands clean, with these latter directives presenting barriers to the possibility of a fuller understanding of how Kathryn's needs and preferences could be best supported within the framework of the study. Such rules became problematic when we were trying to support Kathryn to develop her creative process and it is difficult to peel away their influence on her progress. Despite these difficulties, Kathryn engaged in intense clusters of concentration and play that denoted new material and social endeavours threaded between periods of embedding and the resurfacing of anxieties.
The data did not reveal any particular chronological pattern to this activity, rather a shape of irregularly spaced jumps from cluster to cluster emerged that I began to think of as her *leap-frogging* through the experience of the workshops. Leap-frogging connoted a period of pause, assimilation and uncertainty followed by a period of collecting, collaborating, socialising and experimentation. The element of increased concentration could be said to contribute to the quality of Kathryn's ME in this context as it was where MAs were identified.

Although this doctoral study privileges artistic process over product, perceiving the former to be where creative endeavor and activity is more clearly articulated with this constituency, in describing the works' material aesthetic features by coopting Maclagan’s definition of aesthetics (7), I was able to better notice any change or distinct features that might be relevant to the unveiling of what further constituted ME. The aesthetic features of Kathryn’s paintings did change through her independent efforts, specifically in palette, form and what Maclagan calls the "energies" of the composition (Maclagan 291). This articulated conditions for ME including exposure to the potential of materials through colour
mixing and experimentations with density, scale and support (Process film; Photo thesis). Other conditions included objects of reference and the development of positive relationships with peers. The variety of such conditions is considered in detail in the analytical overview of all the cases, alongside a concluding discussion of the identifiable contexts and conditions that are conducive to the meaning-making capacities of PMLD subjects.

**Case Study 2 - Hayley**

At the time of data-collection Hayley had been attending one-on-one and mixed group sessions at Day Services. For the assessment of Hayley's capacity to consent to participate in the study, I had invited her and a member of the Centre's care and local Occupational Health teams to the meeting. I invited Hayley to view some video footage of people with learning disabilities making artwork; she had leaned in getting closer to the iPad in order to watch more closely. As Hayley did this she said excitedly, “Home Alone!” Bree, a member of the care team, said, “Hayley you like the film don’t you?” to which Hayley nodded emphatically. Bree explained that Hayley had really been enjoying the film 'Home Alone' over the last few months. She would watch the film at home on the weekend and tell staff about it upon her return to the centre. During the week, Hayley frequently referred to the film particularly if looking at a screen on a phone, when she was in the TV room or when asked about her weekend. My Capacity Assessment notes record that I had asked Hayley "Do you want to make a film?" to which she had enthusiastically responded "yes!" accompanied by positive non-verbal affirmations that included head nodding whilst looking from person to person in the room and smiling widely (Capacity Assessment Form, 2014; Reflective Journal).

The next stage in the recruitment process for the study was to conduct Best Interests meetings with key supporters, and in Hayley’s case her mum attended. Liz was enthusiastic and very supportive of Hayley’s involvement in the study to the degree that she wanted to attend at least one of the workshops once they were underway. She said, “I can’t come to many because of work but I’d love to see what Hayley is achieving; she doesn’t get to do too many new activities and I’d like to see her doing new things.” I was pleased at this support for Hayley whilst mindful of my research question; would Liz being in attendance contribute to or distract from Hayley’s meaningful engagement in the
workshops? Liz came up with an idea when we were talking options for her attendance: “I don’t want her to see me really, can I come in and sit quietly at the top end of the room when the session has started?” I agreed to this, “Let’s see how Hayley responds, if she notices you in that first workshop and take our way forward from there. If she is distracted we could look at you watching the workshop through the dining room doors.” We agreed on this as a way forward and said we would try it around week 6 after Hayley had time to settle in (Best Interest Form, 2014).

This case explores a pivotal Meaningful Activity (MA) that took place in week 5 creating a new working process that continued into the remainder of the study. This facilitated development in Hayley’s creative skills and self-reliance. The data is viewed as it unfolds across an extended period of time (Lopez 14) in order to assemble and integrate its constituent pieces into a purposeful narrative. Hayley’s process film, which includes footage taken by Hayley using the HD camera, supports this view.

*Meaningful Activity: Flipping the Gaze*

At the start of the study we knew that Hayley had a strong friendship with Josh. During the Capacity Assessment meeting, Bree had informed me that Hayley advocated for Josh by helping key supporters to make decisions about what he might like to participate in. She said that they often spent time together in the dining room laughing and that the care team recognised their strong friendship. The team felt that advocating for Josh seemed to give Hayley confidence through purpose; this view was recorded in staff workshop evaluations: “Hayley was listless today and not wanting to use the paint. I asked if she wanted to help Josh make a picture, she jumped up and started talking to Josh and shaking his chair. Josh laughed,” and “Hayley worked very well with Josh, she stayed focused for at least 30 minutes” (Network View Appendix G; Staff Evaluation, Week 2). “Hayley enjoyed helping Josh and watching him working on his artwork. She was smiling and laughing” (Staff Evaluation, Week 3). “Hayley wanted to give a dish of paint to Josh which he used to make some finger prints” (Staff Evaluation, Week 2), and “Hayley appeared to be thrilled by Josh’s work. She was smiling and shouting Joshy, good Joshy! Good! Good!” (Staff Evaluation, Week 4).
Up to week 5 the data had shown incidents where Hayley had been energised and focused when she had been involved in Josh's activity, yet her own engagement with the art-making materials continued to be piecemeal and hesitant; she was reluctant to receive praise for her own efforts. I noted that Hayley would look away and to the floor, shrugging her shoulders if congratulated or complimented on her work and had discussed this with Chrissie who was now working with Hayley in every session. She had agreed, saying that Hayley had always responded in this way even before the art workshops had started. She reflected, maybe Hayley is shy? This did not convince me though as I remembered the Best Interest meeting I had with Liz: she had laughingly described Hayley as a ‘diva’ and told me, “she will want to be in control of everything” (Reflexive Journal, Week 4). At times in the early workshops Hayley wanting to direct the activities around her proved to be the only path to her showing interest. In week 5 I reflected, "Hayley had not wanted to make a painting or drawing in the first hour; she was sitting watching the workshop in action and was very quiet until I was about to move a piece of paper on Josh’s desk. Hayley banged the table to tell me not to move it shouting No! Joshy’s, Joshy’s paper! This is the first time she had shown interest in the session today" (Micro Analysis Notebook, Week 5).

It was during the evaluation session at the end of week 5 that I understood how I might introduce an activity to creatively engage Hayley. This was the first week that I had attempted to film the end of workshop evaluations; I thought that I would pick up and put down a small handheld HD camera unobtrusively as assent and dissent positions dictated. Yet during the evaluation I noticed that Hayley was looking away from the camera; she seemed uncomfortable and Chrissie asked, “are you ok Hayley?” I said, “I think it’s this camera Hayley, shall I move it?” I put the camera on my lap and quickly saw Hayley looking up and around again. In an action that attempted to rearticulate the politics of the gaze, I handed over the camera, still recording, to Hayley and invited her to film me instead. My Research Journal reflects Hayley’s response: “she became intrigued and excited with the flip screen in which she could see herself, and began giggling. She was laughing and absorbed by the camera and seemed to be enjoying herself; I asked her whether she would like to use the camera next week. She said yes, and ‘Home Alone!’ I was pleased that we had a possible opening for a way forward that might offer appropriate opportunities for her to engage (Week 5; Process film).
Hayley’s acceptance of the camera critically changed the remainder of her time on the project. It was a key pivotal moment and a shift towards art-making. Upon her arrival at the workshops, Hayley would excitedly ask for it by repeating ‘Home Alone!’ Hayley’s engagement with the camera facilitated a marked difference in the emphasis of her relationships, replacing her reluctance to focus on her own achievements with an eagerness to share what she had captured via her film footage (Photo thesis). Staff Evaluation notes reflect the genesis of this shift: “today Hayley was watching the film that she recorded and hearing her voice on the playback.” I noted that Hayley began to engage with staff and other participants for much longer and with more confidence and focus than she had done previously. She was now very chatty and approached people in the room confidently with camera in hand (Process film; Reflexive Journal, Weeks 6-9; Network View, Appendix F). When Hayley’s mum Liz dropped in to observe in Week 6, we received important corroboration of these perceived changes: “I was amazed Hayley took no notice of me when she spotted me looking in on the project. I found it quite relaxing to be able to sit and watch, as usually when I’m in view of her, she makes a bee-line for me and gets ‘bossy’ “(email correspondence, week 6). Hayley had begun to show a marked increase in agency, taking action on her own initiative. In this filming of others, including the research team, Hayley was now holding a good deal of power; she was in control of the expensive equipment in the room. In responding to the outcomes of these new actions by sharing them with others, Hayley was now making decisions about who was watching whom.

Videoing as a Tool for Mobilising Agency

The footage Hayley captured when watched back revealed her predisposition towards advocating for and encouraging other participants and in this, resonated with a facilitator role. She also showed a range of skills relevant to video making including directing, finding action and framing action (Process film). Her capabilities were increased as she developed the physical strength to hold the camera and move the viewfinder, and the capacity to understand that the viewfinder was where the action would be seen (Process film; Photo thesis). Staff had been standing at Hayley's shoulder to steer her ‘finding’ of different parts of the room or to move the camera in specific ways but this was not working well, serving only to confuse her. Directions were typically; "if you put it down a bit you can see what D is doing" (Micro Analysis Notebook, Week 7). These types of suggestions inevitably resulted in Hayley looking up to find the object of reference, and then down into
the camera lens. As the scale changed dramatically once the visual information was
relocated in a viewfinder, the point of focus was quickly lost. In order to address how I
might facilitate her skills development, I began to move into the workshop space, using my
voice to guide her whilst ensuring a member of staff stayed close in case she should be
needed (Photograph 2, Flipping the gaze). The outcome was demonstrated in a
conversation in week 8:

M: "Hayley can you see me in the camera?...you can hear my voice, I am over here"
H: "Am I?"
M: "Can you see me, can you find my voice?"
H: "Yeah!"
M: "Yeah? Well done!"
H: "Yeah, yeah, yeah!"

These skills began to find momentum in the subsequent weeks, the data articulating
Hayley's work on confidence and the practice of looking: "Joshy!", "that's better!", "there
we go!", "there he is!", "wow! wow!" (Micro Analysis, Week 9, Week 10, Week 13, Week
15). The rise in Hayley's energy and excitement was tangible as she began to gain control
of the camera and successfully find her subject. In week 9 Hayley referred to her creative
output as 'film' for the first time, sharing this with Josh: "Joshy, film!" and I wondered
whether this indicated a growing sense of ownership; during the same week Hayley began
to direct the other workshop participants, encouraging Sharon to "look at me!" The data
and my correlating notes articulated an undulating pattern in this development: "H focusing
well, stable images...then very unstable images and loss of control of the camera," "H
learning to find and frame shots...stating 'there he is!'" (Micro Analysis, Week 8). However,
by week 18 Hayley was working with real focus and beginning to frame steady shots of her
cow-participants (Process film; Photo thesis). Hayley's satisfaction with her filming was
evaluated through her expressions of frustration or happiness which functioned as a lens
of self-assessment ensuring that the team continued to be led by her experience
(Sawhney 179-180).
Initially the visual content that was captured was viewed with Hayley and key supporters within sessions but over the course of the study it was shared with other participants: prompted by Hayley’s requests to show Josh, we set the camera to play back and it was moved around to different workspaces. This footage then, was shown as an affirmation of Hayley’s achievements, exhibited in their raw form to a changing audience of participants and care staff. Led by the ways in which Hayley used the handheld camera, I shaped an
approach to exploiting participatory video: and whilst powerful in its capturing of Hayley’s ‘editing in’ of her experience, it also communicated visually about research as it involved “a whole set of processes that are linked to power, exclusion…(and) voice” (qtd. in Low et al. 59). Those supporting her could reflect on the development of Hayley’s skills; ultimately the footage was an effective means by which to illustrate a number of key features that contributed to the understanding of meaningful engagement in this case. These were:

1) Hayley’s skills development over an extended timeframe.
2) The practical and technical challenges faced by Hayley.
3) The practical and technical challenges faced by myself and care staff in the workshop settings in order to support and develop Hayley to use the camera.
4) The nature and quality of Hayley's interaction with participants and the research team.
5) The points of interest that Hayley chose to film edit in moments of meaning for her and for those looking at the film.

Maintaining inclusive approaches within this case was not without its challenges, particularly in the areas of sensory stimulation, personal space, independence and safety. Hayley was immediately energised by the handheld camera and wanted to circuit within the physical space of the workshop in order to film other participants. At times her presence was an unwelcome distraction, her raised voice creating too high a level of aural stimulation, the camera pushed forward causing unbalance in another participant’s peripheral vision. Deep into the workshop timetable, camera in hand, Hayley suddenly decamped and was located along the corridor outside by her support worker who had been making her a cup of tea. Without ethical approval to film away from the workshop setting, and with visible disruption to other service users unfolding, I had to sensitively invite Hayley back into the workshop space.

Incidents such as these fostered important reflections about the balancing of the study’s inclusive aspirations: I aspired for Hayley to be able to film freely and to gain independence, and I aspired for other participants to work unencumbered. Yet there remained a risk that attempting to optimise participation for all would compromise the quality of its application in the room. An ongoing conversation was established around sensitively guiding Hayley by monitoring the rolling consent positions of both her and those
she was filming, and sharing responsibility for accompanying her around the room in order for staff to rest and observe.

**Meaningful Engagement**

The use of participatory video taken via hand-held camera was unplanned; it emerged organically as a reaction to shared discomfort during Hayley's first filmed evaluation with me. Hayley had added positive complications to my original view on how cameras might be used in the study, adding new possibilities to the ways in which she would communicate her experiences (Rojas and Sanajuha 32; Low et al. 51; Capstick 269) and make the use of the handheld camera uniquely her own. Through it I had been able to align her preference to be in control of her experiences with her interest in social relationships. The conditions that supported ME for Hayley included her ability to mobilise social action including her participating in established friendships, in developing new relationships and in the opportunity to direct and share her experiences.

As discussed, Hayley was a highly influential and cooperative member of the group: she encouraged members to engage in her videoing, and then share the fruits of these endeavours with them (Process film). She did this by stopping at their workstations, approaching them and calling their names seemingly to catch their attention. If a group member looked up or towards her, she encouraged them further, often with, “look! Look! Home Alone!” This was often accompanied by, “well done!” when her preferred subject turned to the camera (Reflexive Journal, Weeks 10, 14). By carefully attuning to Hayley’s dissent positions of turning away and shrugging her shoulders, I had identified a method that would develop both her creative process to ensure greater self-determination, and the space for her visual voice to emerge. The captured footage illustrates this important social interaction and Hayley’s ‘editing in’ of meaning and interest.

There were, however, balances in these interactions that needed careful attention; on one occasion Kathryn became very anxious about Hayley approaching her table with the camera, and she began to shout loudly at Hayley, “away! Go away!” In this instance the balances we thought were in place did not work. Hayley’s presence compromised the conditions for ME for Kathryn who preferred to work with a single carer away from the rest of the group. Balances then, had to be established in the practical application of
participatory approaches in order to maintain working practices that were safe for everyone whilst encouraging new activities to be undertaken in a way that took account of Hayley’s ambitions.

**Case Study 3 – Rob**

Rob was twenty-three at the time of data-collection and had been attending day services with two-to-one support. It emerged that Rob’s support was provided by a changing rota of care staff, some of who were working in a stand-in capacity. The capacity and consent processes showed that Rob could communicate assent and dissent positions non-verbally and reliably by opening his eyes or putting his head down and by tracking or pushing away respectively. I had invited Rob’s mum Lavina to the best interest meeting conducted in a quiet room upstairs in the day centre, she had arrived late from work and apologetic, exhausted she said from, “trying to fit it all in.” Over tea we had a chat about what the workshops might include and how they would be run, Lavina was clear, “you will need to repeat things to him, don’t be miserable, he likes information in a jolly way, you’ll need to be jolly with him. And don’t be too soft; don’t be afraid to push him to do things. And he likes touch sometimes but only when he gets to know you.” (Best Interest Form, 2014; Research Journal, 2014). I had the impression of a woman who really wanted her son to have the opportunity to participate in order to gain new experiences. Lavina told me that she wanted Rob to make some nice artwork and be part of the group. When I next saw Lavina we reflected on this and how challenging but important it had been for Rob to remain in the study. As with the other cases in this doctoral thesis, ME is illuminated here through the thick description (Denzin 33) of two meaningful activities (MA) that took place in weeks 14 and 16.

*Complications of Ensuring Ethical Compliance in the Setting*

Rob’s attendance in the workshops was characterised by poor health; he was only able to attend twenty percent of the total data-collection period, and whilst in the room was often too unwell to participate in any creative activities. One of the day centre Seniors told me that just prior to the study commencing Rob’s health had deteriorated, and his new medications made him very sleepy. As he was receiving them an hour before the workshops started Rob was often in a deep sleep in the medication room next door from
which he could not be woken. When Rob was able to attend his support rotated, sometimes coming from agency personnel who had not worked with him before. I raised this in conversation with a Senior after the first workshop, "I saw a couple of staff members this morning explaining that they would not be attending the session despite being at the meeting yesterday. The rota was showing them doing other activities instead. One staff member also informed me that an agency carer for Rob who had not attended the training would be present. This was of real concern given the immediate pressures of the day and it being the first workshop." The Senior looked under pressure when I stopped her to chat and agreed “I know. I’m really sorry but we had someone off sick and I’ve got to make sure that everyone is covered. I’ll try to keep the people you had in the training with you but I can’t promise.” This was to become an ongoing barrier to the compliance to the ethical framework of the study (Reflective Journal, Week 1).

When Rob was able to attend it was important to myself and staff that we continued to support him, yet doing so presented barriers to meeting NHS requirements for the governance of the project. The conditions of approval were tied into staff giving informed consent to participate and to the recommendation that they attend the reciprocal training day. A few weeks later having been involved in what was becoming the inevitable morning strain of trying to juggle staff to enable all of the participants to attend, I revisited the discussion I had with the Senior. However, this time I requested a conversation at Management level. Janice, a calm woman in her sixties was empathetic and but could not reassure me, “Rob does not have a designated team, he has agency staff who rotate, it’s out of my hands I’m afraid.” I still had a problem: whenever Rob’s agency staff rotated they would be untrained and not meet the conditions of my ethics approval (Reflective Journal, Week 4).

This was not where I wanted the study to be at such an early stage, it would stressful and time-consuming but I realised I had to develop further training and sharing opportunities for agency staff to run alongside the workshops. These would have to be managed in my own time and in the early morning in order to catch new staff ahead of the day’s activities starting. Staff attending these sessions were invited to take home and read the project information sheets, ask for clarification on any points and sign the consent forms ahead of the next session if they wished to be involved. It was helpful that no more than two members of staff attended on any day meaning that they could be delivered intensively
but this extra work on top of my commute to Portsmouth from Cardiff ahead of the workshops themselves, was very tiring.

*Deep Listening and Safe Risks*

Rob’s workspace was next to a table facing a window that looked into the garden and offered lots of light. Occasionally Rob worked in his chair placed further inside the room, closer to the entrance but looking into the space; we needed to ensure that there was plenty of space around the chair for Rob’s two support staff. In either position the chair was infrequently approached by other participants except for Hayley who would note with great empathy, “Rob sleep. Sleep Rob. Hello Rob” (Reflexive Journal, Week 6). One or two people who approached Rob’s table were not participants in the research but were using the room in its other capacity. When Rob noticed these interactions he turned his head towards the sounds made by the approaching visitor, a sign of assent and interest (Capacity Assessment, 2014). The New Road dining room, whilst not a dedicated art-making room worked for Rob socially, contained his table offering him a space to focus on art-making whilst being able to gain from the social interactions described. Additionally, environmental factors could be limited when Rob was unwell or in an intensive period of art-making which required all of his attention, by asking visitors to wait for a few moments before approaching his workspace.

In week 6, Rob was awake and my discussion with the member of staff who had administered his morning medications reinforced my hope that he was well enough to participate in a creative activity. I had two agency staff at the session; both had attended the training earlier that week and consented to participate in the study. One asked me, “what shall we do? Rob is tired.” I asked them to start with using paper of a small scale and to experiment with crumpling it to first create sound stimulation and then to invite Rob to interact with it physically. I reminded them, “we will take our time and let Rob lead by following his consent pattern across the session.” We began very slowly and one of the regular care team members said that she had been anxious that Rob would have to stop if he felt unwell, which echoed around the room in our post-session conversation. We were all rooting for Rob.
Rob was feeling better. In weeks 8 and 9 we sprinkled charcoal onto the paper to try and map his journeying across it. With support, Rob had held onto the small piece of paper and in doing so moved the charcoal around but he was unable to sustain this as one of his carers reflected: “Rob pushed away with his hand…(he was) so tired and fell asleep” (Evaluation, Week 9). Despite this, Rob had shown some interest in the material and I felt that if he were more energised, this approach might be developed towards independent contact. One way to do this was to begin to increase the scale of the paper in order to create an auditory pathway thereby supporting Rob to independently engage with the materials if he wished. In week 14 and after a period of absence, this approach coincided with a positive improvement in Rob’s health and a change of pace in his engagement with creative activities. In their end of session evaluation, his carers noted, “Rob was noticeably more alert and awake today” and in response to the question ‘did anything new happen?’ they stated “he had independently moved his hand over the paper and dipped his fingers in the charcoal” (Staff Evaluation, Week 14; Process film; Photo thesis). In our end of session chat, the broader team of care staff had noticed the positive change in Rob. Whilst we cleared up the dining room, someone said, “Rob really enjoyed that paper today didn’t he? The sounds and the feeling of it, I thought that was great for him.” Those gathered around agreed, and I came away thinking about the potential of the material.

**Meaningful Activity 1: Paper Dance**

In the next session I introduced Rob to a large piece of plain white paper robust enough to withstand the demands of repeated physical contact, beginning with crumpling and moving towards placing it across the front of his torso (Process film). The scale of the paper presented a new experience for Rob and a fresh way of working for myself and support staff, and I was mindful that we must continue to adapt my approach *in the moment* in order to establish where there might be room for his process to grow. In this dynamic space there was the interpretation of *safe risk*, an idea I was developing about the creative-enabler practice that harnessed emerging knowledge. When viewed at 50% of its original speed the process film for this Meaningful Activity (MA) provided a thick description of this in-the-moment engagement. It shows our employment of deep listening to follow Rob's lead as he worked towards and ultimately made his first sustained independent contact with the paper. In this MA it was critical that the staff member and myself sensitively moved around the ebb and flow of hands on the paper-scape and
tracked Rob as he negotiated the terrain safely; to support this I provided cues through touch (Process film).

**Meaningful Activity 2 - Drawing Sculpture**

As discussed Rob had been introduced to paper both through touch and as auditory stimulation created by scrunching and twisting it close to and on his body (Process film), in addition charcoal had been used in a limited way. In week 15 I revisited the idea of safe-risk by introducing black compressed charcoal to his session. My research journal noted "Rob was re-introduced to the material this week after a sustained period in the research where he has not been able to engage in making due to ill health. Rob was working on a large piece of paper by assenting to it being lightly crumpled on his torso. After some time I quietly introduced him to some compressed charcoal that I had applied to my fingertips. Rob assented to my touch and directed his hands towards the paper where he was able to make some initial, tentative marks. Two members of staff then applied a little pool of charcoal onto the paper and he continued to work with the material by softly pushing at it with his fingertips. We discovered that the pooled charcoal limited the potential of both materials to retain Rob's marks as his reach was very contained" (Research Journal, Week 15; Network View, Appendix F).

I was interested in the potential of the soft compressed charcoal. The material was very light but incredibly dense, having the texture and malleability of cooking flour. In the subsequent session I housed the charcoal in small round metal and plastic dishes around two inches deep and three inches across. Containers of this scale and depth could be easily maneuvered and when placed near Rob's hands below his fingertips, provided him easy exploration of the charcoal (Network View 1). When Rob chose to reach out and explore the charcoal the person holding the dish would provide a solid platform for it, simply holding it still (Process film). From Rob's first tentative explorations where he would pull away when his fingers made the lightest of brushes against the surface of the dish, we witnessed a rapid progression towards an MA.

Rob began settling his fingertips in the charcoal and leaving them there. I was holding the first of the little charcoal bowls steady, internally overawed at Rob's courage and determination, whilst externally trying to maintain an air of calm. In his imprinting of the
material Rob created marks that articulated the places where finger pads and tips had rested and pulled backwards, upwards and outwards, creating dunes of raised charcoal established against the sides of the dishes (Process film; Photo thesis; Photograph 2 Charcoal Dunes). The range of marks Rob made in this material created three-dimensional archives of his journeying and in this sense they could be thought of as pieces that crossed traditional artistic boundaries. The pieces used common drawing materials yet evolved as works that might be defined as sculpture. In that they showed traces of his making and came about from his lived reality Rob's pieces were "objects of concrete experience" (Dewey 10) yet in them remained a sense of fragility in that they could be easily altered by kinesthetic disturbance (Photo thesis).

![Charcoal Dunes](image)

Photograph 2 ‘Charcoal Dunes’
Melaneia Warwick  Original in Colour

The social model of disability helps us articulate barrier removal by shifting “cultural assumptions about the disabled out into the open for examination” (Quayson qtd. in Davies 204). By following the trajectory of Rob’s creative work I was able to understand his interaction with the material as one that transcended its traditional function. This reconception of the boundaries between drawing and sculpture blurred presenting an
alternative dialogue about artistic genre, as charcoal normally destined for flat paper became an object in itself.

Barriers to ME

In relocating making outside of the studio and into Day Services this study disrupts the "compartmental conception" (Dewey 6) of art placing its access into the lives and communities of people with PMLD. Yet aspirations to research inclusively with this population are challenging, fluid and complex. Rob's poor health presented a barrier to his ME as he struggled to stay awake during all of the early sessions he was able to attend. Additionally the frequent change in his care staff meant that I found myself with an extra time burden to adapt the research processes to include mini staff sharing sessions. These ensured that I remained compliant with NHS ethical approval and critically, that Rob was supported to engage in the workshops in a consistent way. Nind articulates the ways in which attempting to meet the “qualities desired of participatory or inclusive research” (What is inclusive research? 91) can present the researcher with hardship and industry and I found this to be the case as my role was stretched thinner.

There is a distinct aesthetic quality in the proportion, harmony and blending of the right facilitation-enabling approach needed for each of the cases in this doctoral study. Rob promoted me to view my practice in new ways through the refinement of my approach. By developing my ongoing guidance to staff members I enabled new opportunities for independence to be developed (Photo thesis; Process film). Through this approach I was able to see how Rob developed his own momentum, reaching back out towards the material unprompted; it is possible to read curiosity and bravery into these movements. In his process of making there is movement, suspense and a return to movement before a resolution is reached by a period of stillness within both the paper and the charcoal, and in this the materials provide a site for safe-risk.

Rob's ME then, was not simply a result of his material outcomes but is clearly linked to his process for making. What characterises the identified MAs as part of Rob’s creative practice is that they were sustained in the weeks following their emergence. Rob continued to work with compressed charcoal, creating a compelling series of works in black and sepia. His grandmother in conversation at a coffee morning I held in week 17,
noted the expansion of his experience reflecting, “I have never seen Rob touch anything like this, he normally won’t do it. It’s lovely. I can’t believe how much he has achieved and he’s been so unwell. We wish he could have stayed in more sessions so we could see what else he could do” (Research Journal, Week 18). What Rob had achieved in the last five workshops presented a major stage in the development of his creative process and indicated that his ME relied on a number of key characteristics. These were: regular attendance, consistent staff messages around project approaches, safe-risks, deep listening and the voices of his key supporters.

Case Study 4 - Charlotte

This case study centres on the ways in which Charlotte's creative process developed leading up to and after a decisive Meaningful Activity (MA). As with the other cases in this thesis, it assesses the MA in an expanded data field enabling it to be viewed beyond a single critical moment by considering its contributing factors and enduring influence. At the period of the study, Charlotte was attending New Road Day Centre where she was participating in individual sensory room sessions and dining room social activities with other service users. Her Best Interest meeting revealed that Charlotte had previous positive experiences of arts activities and that she would enjoy the group setting, reinforcing my initial impression that she was "a sociable person" (Best Interest Form, 2017). Charlotte’s Capacity Assessment highlighted that she used reliable methods to communicate consent, interest and their opposites through eye contact, gesturing towards, laughing or through neutral expressions and looking away. In conjunction with the subsequent Best Interest observations, this meeting indicated that Charlotte would benefit from objects of reference such as soft paintbrushes or sponges to support her understanding of information (Capacity Assessment Form, 2017; Best Interest Form, 2017). We also noted that Charlotte was very interested in watching a film about previous participatory art workshops, and that she might later wish to work with the GoPro camera.

Material Curiosity as a Tool to Advance Visual Vocabulary

The purpose of the workshops was to ascertain what materials might be suitable for Charlotte to begin working with whilst I remained cognisant of staff reports that she had limited mobility in her hands (Reflexive Journal, Week 1; Process film). Two clear factors
impacted the material options: the ability for them to be responsive to Charlotte’s range of movement and the potential for them to offer clear dichotomies with which to appreciate her preferences. I limited material options to those which experience had taught me were extremely malleable: paint, charcoal and paper offered variously cool, warm, dry, wet, thick, thin, soft, dense, smooth, and lumpy sensations/characteristics and a range of scale and textural options were provided both by the support and tools offered.

At the start of the study Charlotte's range of hand movements meant that she was able to work with charcoal solely in its powder form. However, she showed an interest in charcoal sticks, reaching out for them when they were offered and with continued support she was able to hold them in her closed fist, albeit with frequent dropping. This was evident in week 4 when she showed real determination to hold and move the charcoal stick, with care staff noting, “she concentrated very hard to draw on her canvas” (Staff Evaluation, Week 4). In the first 8 weeks of the study, a growing interest in this material supported Charlotte’s creative process in a number of ways:

1. She was able to reliably hold the material for increasingly longer periods of time.
2. She was able to move the material further across the canvas support.
3. These physical changes enabled an elaboration in Charlotte’s visual language: the data shows longer, darker, more certain lines and smudged traces denoting where these were revisited.

(Network View 2 Appendix G; Process film)

Initially, Charlotte had chosen to paint with her right index finger, which she reached out and curled into a 'c' before dipping into the small pots of paint offered. As the study evolved, she began to expand the ways in which she used her hand to make marks with paint (Network Views Appendix G; Process film). The data reflects this elaboration: "C worked on her back in the garden today and made some small-scale acrylic pieces using her index finger.... Jayne commented on the extent to which C was now stretching out and opening her right hand in the sessions. C seemed very focused at times, looking intently and concentrating very hard on her [art-]making" (Reflexive Journal, Week 3; Network View 1; Process film). Charlotte's increasing mobility in her hands began to materialise as an important development in the workshops as care staff noted, "What was meaningful to
Charlotte was concentrating by extending her fingers out to paint onto her canvas", "Charlotte held charcoal", and "Charlotte moved her whole hand to complete her paintings" (Staff Evaluations, Week 3, Week 4, Week 7). Key to Charlotte’s unfolding creative fluency then, was a consistent material curiosity that promoted increased dexterity and focus.

*Meaningful Activity: Double Canvas*

Charlotte had continued to use her right hand in her art-making with her left resting on her lap or chair, but during week 8 there was a significant change to her way of working resulting in a pair of canvases being created simultaneously. I had been supporting Charlotte in her charcoal mark-making as she was finishing a canvas and noticed her left hand index finger moving and stretching. My Reflexive Journal notes state, "I thought that C might be ready to try working in series as it seemed that she was stimulated, through her right hand mark-making, to move through her left hand. We had two small blank canvases remaining so I asked H to unwrap them and invited C to dip the index fingers of both hands in the pink paint she had chosen. I supported both canvases in her plane of movement and vision and C chose to work on both. She was visibly energised and focused, moving from one index finger to another whilst laughing. Notably, C's marks were quite different: they were much more smudged as she worked the sides of her fists into the paint as well as scraping and pulling with her fingers. C chose to work with gold metallic paint, producing some slightly more pronounced ridges as well as the smudged marks" (Reflexive Journal, Week 8; Process film; Photo thesis; Network View Appendix G).

Working with both hands in this way acted as a way marker for a subsequent series of new experiences. These clustered around weeks 10 to 19 when Charlotte began to use different tools including paintbrushes and a palette knife, began to mix her own paint colours and commenced work both on a large-scale and in series (Process film). The process by which Charlotte was supported to mix her own colours came from a working conversation I was having with Jane and Charlotte during a session. Charlotte had been using a large paintbrush with blue paint, and as she lifted her hand to the canvas, a string of stray yellow paint from her finger merged with the blue. The resulting streak of green visually jumped off the canvas; I was excited. “Charlotte I think you are mixing a new colour here by what you have done with the blue and yellow"; I said this whilst pointing to the new colour on the canvas. Charlotte laughed, often an assent position she used to
show her interest. I suggested, “if you like we can try to see if you want to mix more green by putting some yellow on your finger?” Charlotte raised her arm in assent as Jane simultaneously showed her the yellow paint pot and we invited her to dip her finger into the paint, standing where we were not overcrowding her. The colours combining caught Charlotte’s focus and she continued to accept yellow paint and to apply it to the blue on the canvas. We were able to support Charlotte to work in this new way for the remainder of the workshops. Staff Evaluations reflected the continued changes: “Charlotte was using the fleshy bit of her hand (near the thumb) to mix colours today” and “she mixed new colours she does not normally use” (Week 13, Week 14; Network Views, Appendix G). The processes used to support Charlotte to choose materials are illuminated in the Process Film, which acts as a visual means of providing a thick case study description (Denzin Chapter 3).

The Principle of What Else?

In the messy, unpredictable space that was the dining room, it was important to identify and remind myself of the conditions that might legitimise and restrain ME. One of these was the previously discussed deep listening skill required by the creative-enabler, here necessary in order for me to be able to respond creatively to the new movements Charlotte was making prior to the ensuing MA. Through working with Charlotte I understood this as an emerging principle I conceptualised as What Else? This principle implied alertness to the communication of the participant and a willingness to respond creatively where there were shifts at the boundaries of their working approaches. Approaching the workshops in terms of What Else? enabled Charlotte to self-advocate by articulating her material ways of knowing and responding in the moment and fostered a positive attitude on the part of supporters. This took the form of personal responses and perceptions about Charlotte’s experiences. Examples of the former included "her work was brilliant!", and "everyone was pleased and impressed with her work", "Charlotte 'Picasso' Hawkins!" (Staff Evaluations Week 8, Week 10, Week 14) and latterly, "I believe Charlotte was proud of what she achieved today", “it was meaningful to Charlotte to see how impressed and pleased everyone was,” and “Charlotte was really happy whilst doing her canvas!” (Staff Evaluations Week 8, Week 9, Week 15).
Although the data collected were unable to ascribe definitive intentions to Charlotte’s finished canvases, there were many responses to them as pieces of art as described. Maclagan’s discussion on psychological aesthetics demonstrates the existence of an independent space outside of the usual conversation between artistic intention and viewer projection through which artworks can be viewed. This space is defined in part by a reaction to the processes utilised in the artwork’s creation: the way in which marks are made through the materials used, what Maclagan terms its "material qualities" that can be thought of as having an "existence independent of the state of (the artist's) mind" (20). Instrumentalising Maclagan’s position within this case study constructed a helpful way in which to understand how the artworks might be being viewed. This was both through a process lens, and with audiences involved in a collaborative meaning-making experience in which they were able to develop shared meanings. In doing so they have the potential to develop appreciation of, and insight into, the creative endeavor. On week 18 we held a coffee morning for families of participants to which Charlotte’s parents came. Her father was tearful as he told me, “I can see how happy she has been, she loved painting at school but they had to tie a brush to her hand because she couldn’t hold it. It’s amazing she held the brush by herself.” I took a moment to reflect on how glad I was of the distance travelled since such practices were used (Reflexive Journal, Week 18; Photograph 3 Working with a Brush). For Charlotte’s supporters, both in and outside of the workshop setting, observing the works in progress was absorbing and engaging. It offered a unique opportunity to see her overcome physical, cognitive and social challenges in order to respond in the moment to her environment and the materials she was using. In this way Charlotte contributed an important motivational tool to those supporting her creatively.

The ways in which the material qualities of artworks exist outside of artistic intention illuminates the importance of the potential of the materials themselves. If materials are to enable the moment-to-moment experiences of people to be retained, they must be viewed as an imperatively important part of the work. In this case study the agency of materials was enabled because they were of a suitable quality to perform by staying open, retaining marks with clarity, maintaining colour and consistency and mixing well.
Meaningful Engagement

Although the data collected could not be used to attest that Charlotte was consciously attempting to make art, it enabled me to understand her engagement as responding in the moment to a number of environmental conditions. These supported her to reach outward with, and to, her materials and to move them against the support offered. The marks Charlotte made over the course of the study changed significantly as new creative opportunities were afforded her (Network View, Appendix F).

Critical to the participatory arts outlined in this thesis was the wish to leave a legacy of engagement and living approaches for it to continue in the support setting. When Charlotte’s moving hand had led to my support of her working on two canvases, carer Harriett had continued to work with her to complete the pieces (Reflexive Journal, Week 8). The act of developing professional arts expertise in care staff served to address intimidation that could lead to future inaction, particularly if staff were previously concerned that they could not support people to use arts materials effectively. Charlotte’s important
contribution was in fostering positive projections about, and empathetic interest in, her experience on the part of supporters. By following her lead, we were reminded that she was enabling others to look differently at her abilities and strengthening her relationships with them via a practice that had the potential to engage through its personal interpretation of meaning.

Case Study 5 – Danielle

This case study will look at a developing picture of meaningful engagement with particular focus on a five-week period at the end of the data-collection phase. At the time of the study, Dani was a twenty-five-year-old woman who had previously enjoyed jewellery making and drawing with coloured pens in sessions provided at the centre. Staff agreed that she would enjoy using paint in future as she enjoyed ‘messy’ working and Dani had shown us that she did have an interest in trying new materials.

Myself and Jo, the Senior Occupational Therapist advising me on the ethical phase of the project, undertook Dani’s Capacity Assessment. Jo knew Dani well and had informed me that she had a reliable range of verbal and non-verbal communication including nodding and shaking her head and saying ‘yes’ and ‘no’. We met Dani at Reception in the Kestrel Centre, a support facility for people with learning disabilities. I quickly had the impression that she wanted to direct the meeting as she took charge in leading us around the Centre to find a space where we could chat. Jo had asked at Reception, “Dani, shall I find us a room?” to which Dani shook her head emphatically, “no!” and headed off in her wheelchair. We took this as a sign to follow and did so, breaking into a trot to keep up with a grinning Dani. I was delighted at how empowered she was. Jo said later as we discussed the meeting, “she’s really strong and knows what she wants,” “yep, brilliant,” I had responded. Jo had warned against my taking a long-term view: “she has not attended anything consistently though, and you will probably find that she drops out of your study after a few weeks.” I was interested: “why’s that?”, “she gets bored I think, we’re not really sure but she will let us know she feels unwell and will tell us she wants to leave the sessions.” I remained hopeful that we would find something to engage Dani in but realistic that she might simply not wish to attend, that the sessions may not be meaningful for her.
This unpredictability was to set the tone for my future interactions with Dani. Two key areas of note had been raised during the recruitment process: attendance and independence. The established pattern of unpredictability related to other day care sessions was not fully understood by staff and I knew that this might present a risk to her full attendance of the workshops. I also learned that independence was very important to Dani and staff would often respond to this by leaving her to work alone; I wanted to develop a line of enquiry around this approach and how we might support Dani to stay in the workshop space. Dani would go on to attend thirteen of the twenty possible workshops, initially consenting to stay in the room for around thirty minutes with a significant increase up to an hour and a half towards the end of the data-collection period. This case investigates the conditions that supported this change and how it led to a Meaningful Activity in the last few weeks of the study.

*Meaningful Activity: Cheerleading and Canvas Bags*

Over the first 8 sessions, Dani experimented with painting and drawing in a range of ways preferring to focus on them for short periods of time and then choosing to either leave the workshop or move onto another material approach. Staff feedback for these sessions concentrated on these challenges and illuminate the pace of change: “Danielle put the trigger spray down on the floor and removed apron and shirt”, “Today Dan enjoyed the session for 15 minutes, which is great, then wanted to do something else” and “Dani joined the session for longer” (Staff Feedback, Week 2; Week 4; Week 8). I noticed that Dani’s carer, Kelly, always stood away from her workspace often watching tentatively from a distance and in one session I asked her about this. She said that she did not want to crowd Dani and was worried about compromising her independence; she was anxious about how best to support her to stay in the room. Soon into this conversation I thought that this theory needed testing, perhaps Dani was loosing interest *because* she was being left to work alone. Would there be a difference if someone was supporting her, and what shape might this support take?

I decided to simply sit at her workspace and take an interest in her art-making to see where this might lead, acknowledging my own discomfort in that I did not have a plan beyond making the work the centre of my engagement. A few comments in, I had decided to model being an artist’s assistant, asking, “Dani shall I pass you the paintbrush?” to
which she looked intently at the pot of brushes and replied “yeah” and then quickly with a head nod towards the preferred brush, “big one.” Dani was beginning to give me direction. I reflected with Kelly later, “did you see Dani working today? She was extremely excited, doing a dance in her chair. It is the happiest I have seen her in the workshops so far. It seemed to be linked with me supporting her to be in control of how things would go.” Kelly was smiling: “yeah I know, I’m in shock. It was her best session so far” (Research Journal, Week 8). The nature of this support was important though; we found that Dani’s focus and self-satisfaction correlated to her “doing” as discussed by Mansell and Beadle-Brown (17; Network View 1; Appendix G) rather than passively listening or watching. This was a critical factor in what I came to understand as ME. Supporter interaction seemed to be purposeful when it was “encouraging, prompting, helping” as advocated by Mansell and Beadle-Brown (17) and I began to think of these aspects of our facilitation as cheerleading, an approach that provided motivation aligned to the creative activity at hand through positive focus and reinforcement. Dani showed us that cheerleading worked best when it was consistent and directed by her. Specifically, she enjoyed being observed in her art-making (Process film; Photo thesis) and being left alone at the workspace would result in her quickly downing tools and materials. Whilst Dani began to stay in the room longer, socialise more and increasingly express enjoyment, she had not yet created any artwork that showed a sustained focus with materials.

The activities that Dani had been involved in up to week 14 had, often necessarily, been piecemeal and fragmented: small paintings of red love hearts, one or two paintings in the garden made with a range of watered-down colours poured into gardening spray bottles, and a bit of charcoal drawing. I wondered if we could turn her new enjoyment of the sessions towards new creative materials. Kelly had approached me in the dining room asking if Dani could make artwork that she could take home and display there; we had been storing all of her artwork in a large personalised folder at the centre. I wanted to offer Dani something that would hold her attention and began to think about her life more broadly for inspiration. We discussed this: “Dani, what do you really like to do?”, and with a big smile and no hesitation, Dani shouted, “shopping!” Kelly looked at me, grinning too: “she is always wanting to go shopping!” I had an idea: “why don’t we buy some blank canvas bags for you to paint on Dani, for your shopping trips? You could take them home and use them whenever you liked.” I showed Dani a picture on my ipad and explained
again with Kelly supporting; Dani was dancing in her chair again (Research Journal, Week 14).

Staff feedback for the following session was markedly different in tone to what had preceded: “Dani was excited to paint on a bag with her own design”, “Dani said - oh yeah” and “Dan was very enthusiastic” (Staff Feedback, Week 15; Week 17; Week 16). There was also important commentary around ownership of the bags: “it was meaningful to Dani to be able to take home artwork that she can use” (Staff Feedback Week 16). I added more elements to Dani’s workspace: a range of artists’ books with natural themes such as semi-abstract photographs of land and sea, more paintbrushes, bowls for mixing colours and a pot of water (Process film; Photo thesis). We looked through the books together, where my role as assistant was to turn the pages and ask questions about which images Dani liked best. Once we had agreed on five images, these would be transferred onto a separate bag – one for each remaining week of the data-collection period if Dani agreed this in the following sessions. The images in the books were essentially colour fields and I thought that Dani could easily translate them onto the bags without her having to draw complex forms. Helpfully the books were small enough to be propped up in front of the bag she was working on for reference (Photo thesis).

A pattern of material competence and focus on her process developed over the last five weeks of workshops, as did the length of time Dani was choosing to stay in the room. She had moved confidently from painting motifs such as love hearts to gaining input from images of nature in artists’ books. There was a change in her demeanour once cheerleading was established: during week 16 Dani began to charge me with holding her mixing plate in a way that allowed for easier access (Photo thesis). By week 19, staff and myself were holding and passing paints, brushes, palette knives and the mixing plate that Dani was working with (Network View Appendix G; Process film). Dani was serious in her little studio - the propped up source books in her workspace offered a concrete focal point and access to new tools such as a palette knife, mixing plate and designated paints, all which delineated ownership (Photograph 4, Pop-up Workspace). There was a depth to her experiences that seemed to be supported by these elements. What had previously been distracting in the noisy, busy dining room was no longer a factor in compromising Dani’s focus and she worked with relish at what had become a highly personal series of bags (Photo thesis).
Meaningful Engagement

A barrier to Dani’s meaningful engagement was to misconstrue her independent nature as a desire for solitude, and in our coming to understanding this, we had inadvertently continued to create this barrier. Through increased opportunities to work with Dani consistently, I was able to discover that cheerleading worked well for her as she retained a high level of control of her developing creative process. Indeed it was through supporting this highly individualised approach that her independence was maximised. The conditions for meaningful engagement in this context emerged as facilitation through cheerleading, consistent attendance of workshops, creation of artwork that was directly related to the leisure activities of the participant and a designated workspace (Photo thesis). Although the latter was impractical as a permanent fixture between workshops, I was able to set up the space ahead of Dani’s arrival in order that it was familiar and identifiable upon her entering the dining room.

Meaningful engagement was also supported when Dani was able to stay in the room for longer periods. It has been acknowledged elsewhere in this thesis that extended periods of time are essential in getting to know people with complex disabilities. In Dani’s case, her consistent attendance and the development of an activity that she really bought into directly affected each other; the data showed that these situations emerged across the same period of time. Through her development of a series of designs for shopping bags, Dani was able to express herself and in her claim on the collection of these pieces, she reminded us that retention of artwork must remain the right of the maker.
Case Study 6 – Josh

This case study will look at two meaningful activities by setting the scene for their occurrence within an extended timeframe, taking Lopez’s notion of differently-viewing the temporal framework of a phenomenon in order to situate oneself “within a dynamic event” (Lopez 14). In order to establish these, I draw on the events leading to and away from them and in doing so note the subsequent emergence of established ways of working that are echoes of these meaningful activity moments. The chapter concludes by drawing together the data to describe the conditions that have created a meaningful engagement context for Josh in the context of this study.

The network view function of Atlas.ti (Network View Appendix G) illuminated an interesting story of Josh receiving and beginning to explore new materials and develop art-making processes, and critically how this exploration gained momentum and moved into activity that was unfamiliar or original. The film data proved particularly useful for identifying this, but in order to locate this story in a thick analysis of events after Denzin and really see the factors contributing to MA moments, other data were investigated; the key event moved
into soft focus. Further data included staff attitudes and observations, the impact of others in the room, Josh’s work area and the general workshop space. These factors were taken into a series of network views in order to create a multi-layered picture of Josh’s experience in the study.

Relational Practice: Space Hopper

The space hopper\(^{2}\) was an established favourite item of Josh’s prior to the project starting, having been used by staff over the last year for its potential to stimulate and energise him. Yet it was a toy, in particular the kind of object associated with children’s play and potentially risked infantilising Josh’s art-making processes. I wanted to fully explore its potential, to ask whether its inherent value to Josh outweighed my perceptions, and to offer Josh other auditory stimulation options in order to compare his preferences. It was being used both as auditory and physical stimulation through rapid compression that caused it to produce a long drawn-out squeak against Josh’s chest and arms so that its inflation and deflation could be felt. Steve, who had worked extensively with Josh over the last year, told me how much Josh enjoyed interactions with the space hopper. One day, really early on in the workshops, Josh had been sitting unusually quiet at his workspace and although Steve and I had been trying to get him interested in the arts materials nothing was lifting his energy. I was reflecting on how we might best engage Josh and asked, “Steve, is there anything else Josh would like in his workspace do you think, what normally lifts his energy?” Steve said, “there’s the space hopper, he loves it. I think it’s in that cupboard, we’ve used it before when he’s been a bit bored, makes him laugh when it squeaks.” I was encouraged and went straight over to the cupboard where I found a mini version of the bouncy space hopper, small enough to be held in two hands with a really loud, pitchy squeak. As soon as I compressed it from within the cupboard Steve shouted, “he’s looking for it and smiling!” Great! I went straight over with it and began to compress it near Josh and then onto his arms and chest under Steve’s guidance. After a few minutes of this Josh was energised, running his thumbs through the compressed charcoal and creating clusters of crisscrossed powdery lines (Reflexive Journal, Week 2; Process film).

\(^{2}\) A heavy rubber balloon with two handles at the top that a child can use to sit on in order to bounce up and down. Josh had a handheld version of the space hopper.
Explorations of the film data and staff feedback revealed a great deal of consistency around Josh's reactions to the space hopper. These included laughing, smiling and verbalising in ways previously identified through the consent and capacity processes of the project as assent. It was clear through these signals that Josh was happy and enjoying himself. A regular pattern emerged in that when the space hopper was being used, the sounds it made seemed to provide both interest and focus. Josh would frequently turn his head towards the noise from its initial compression and after expressing enjoyment would follow this with a renewed interest in his materials (Process film).

An important relational aspect of the practice emerged from the enquiries linked to the space hopper and specifically through its use and response by Josh, Steve, a close friend Hayley, and myself. There were some insightful incidents of mirroring where Steve's rhythmic compression of the space hopper was simultaneously played out through Josh's banging on his worktable (Process film) and in my use of the space hopper as a tool to support Josh to work with boards and clay (Process film). Hayley's noisy compression of the space hopper was obviously undertaken for Josh's enjoyment but it was clear that both parties enjoyed his laughter. Where deep listening was shared between Josh and a supporter, mirroring occurred showing a mutual understanding in the non-verbal conversation (Process film), and this could be contrasted against other incidences where, despite Josh continuing to assenting and making work, mirroring was not evident between him and a supporter.

*Brown Paper and Bells*

I had asked for a meeting with Janice, the day centre manager, to talk about an idea I had to support Josh in making some Hapa prints. These would involve Josh using a hammer to compress plant material onto paper. Janice had said with some uncertainty, “well how is Josh going to know what to do with that hammer, how are you getting him to hold it?” I was keen to try something really physical with Josh because of the preferences that had been expressed in his capacity interview: “if I can think of something are you happy with me trying it? Josh enjoys physical experiences so I think we need to be providing some. Obviously in an enjoyable, safe way. He might benefit from a bit of risk.” Janice tentatively agreed on the proviso that the hammer was stored in my car after each session: “I don’t want it left lying around, it could cause damage” (Reflexive Journal, Week 2). In the next
session I was talking to Steve about how we could support Josh to become familiar with the hammer. Steve said, “let him reach out his hand and we'll put it near so he can find it and explore it.” I wanted something a little more immediate and said I would think about it a little more. Back in my office, I had a recollection of using bells in other settings as auditory pathways for people with visual impairments (Reflexive Journal, Week 3).

The next week I tied a string of bells to the hammer handle and shook them in order to support Josh to make contact. Once Josh had developed a familiarity with gripping the handle, the bells became redundant. Very quickly we saw an increase in moments of independence where Josh chose to hold and let go of the hammer and by week 5, Josh was reaching for, or indicating a wish to make contact with, the hammer (Process film). Though the bells became redundant, Josh's non-verbal communication became clearer. Josh had begun to knock his worktable surface with a closed fist in what seemed to be an indication that he wanted to make contact with the hammer. In week 5, Steve had said, "he's hammering, he wants that hammer he does, he’s asking for it" and my reflective notes from the same week query this new action: "J exploring paper then hammer. Then making a knocking action. Is there a connection?" In a data triangulation session with staff the following week, the connection Steve and I had perceived was corroborated by staff and Josh was indeed asking for the hammer; our relational practice had developed further (Reflexive Journal, Week 4; Data Triangulation, Week 5).

This advancement in the relational practice developed the scaffolding on which to build new pathways into auditory stimulus. I had begun to use scraps of brown paper in week 2 after noticing Josh was turning his attention to a piece that was being crumpled; it was a cheap, readily available resource and could be recycled back into the sessions if needed. By week 5 I had changed the scale of the stimulus by introducing large unused sheets, and my Atlas.ti notes for the film data read “using brown paper to signpost J towards printing.” Directly after this stimulation, Josh began to make the early gestures that would be seen fully in MA 1 to express a more directed interest in the paper and inform subsequent experiments with materials and MA 2. I noted, “Josh was reaching for stimulus (paper)…choosing to keep his hand on it as it is being rustled”; at week 6 I coded Josh’s activity and the related auditory stimulation as process for making.
Josh's responses were imparted via clear signals conveying empathy, mirroring, renewed or sustained focus and rich enjoyment. Seen through a lens where Kester's littoral art as a “point of complimentary meeting” (The one and the many 1) meets the inclusive relational practice described in Nind as “pluralities of knowledge” (What is inclusive research? 69), they can be reframed as encouragement to supporters to continue to use a particular tool or material. Yet in participatory arts work with adults with PMLD, this relational practice must be perceived over an extended temporal framework in order that the rich threads of connectivity, the fuller causal pathways, are not simply reduced to the ‘main event’ and a few contextual markers.

Meaningful Activity 1: Week 7

In week 7, Josh was invited to engage in the full process of Hapa printing with support from myself, Steve and Mark. We began with plant material collection that involved a journey around the day centre garden. This was the first of many lively trips, and Mark, a chatty person involved us all in his frequent jokes, often getting Josh laughing. We traversed across the large, bumpy grassed area to the borders and bushes and into the entrance of the dilapidated greenhouse in the sunshine. I invited Josh to smell, touch and hold the plants; we usually spent thirty minutes exploring in this way before returning to the workspace to make prints. I said to Steve and Mark, “I want to make sure Josh has a fully rounded appreciation of the plant material, let’s make sure he has experience of it before, during and after printing. It will smell and feel completely different in these stages” (Reflexive Journal, Week 7).

A number of striking Hapa prints were made using a collaborative process: with bells attached to the handle and Josh holding on, Steve would make a banging action with the head of the hammer. Whilst Josh continued to assent to holding the hammer and exploring the plant material in its different phases of change, I felt that his process could be more independent and continue towards hands off or light touch support. Steve, Mark and I discussed bringing in different plant material, and standing back to enable Josh to lead the next phase of the creative process. Mark agreed, “I think he’ll like it, why don’t you see what’s in the florist up the road.” Soon we all wanted a new selection of flowers and were talking enthusiastically: “I reckon we should try roses, they smell stronger than what we have got in the garden”, “I'm thinking lilies!” For the next workshop I bought some fresh red
roses in, stems cut to avoid any thorns. Steve ran them over Josh’s hands and put them under his nose. We noticed that he quickly opened his hand to grasp them and at this, looked at each other: “he likes them!” Josh reached out to find the flowers (Process film) and began to drag them across the paper by using the thumb of his left hand. In this and with subsequent flower material, Josh was completely absorbed, creating dynamic marks on paper (Process film).

*Meaningful Activity 2: Week 11*

During the early workshops Josh had been introduced to the sounds of sheets of brown paper being crumpled but had not tactiley engaged with the material. The creative potential of the Hapa printing work was concluding and week 11 marked the opportunity to follow an embryonic pathway that Josh had been marking out. In the last two sessions, he had begun to move the printing paper across his worktable with his thumb creating minor creases and dimples in it. There was emphasis and repetition in these actions but a lack of flexibility in the material meant that it did not respond as it might. A logical next step was to invite him to explore large sheets of brown paper. This softer paper provided a new material terrain known for its creasing properties, it was louder than the cartridge paper and could provide a link between physical movements and the resulting sounds created. It also transpired that it was robust enough to withstand sustained exploration (Process film).

Josh had been interacting with Hayley earlier in the session of week 11, smiling and responding to her calling out his name whilst filming him; he was enjoying audio and physical stimulation with Steve and the space hopper (Process film). Steve and I had established in earlier work conducted that we wanted to give Josh plenty of time to interact with new materials and so we decided to leave a large piece of brown paper flat on his worktable in front of him. We remained around the table where Steve was talking to Josh and inviting him to explore the paper saying, "c'mon Josh, come and see what this is" to which Josh raised his head and turned towards Steve’s voice. I added my own encouragements and the occasional compression of the space hopper in the vicinity of the paper. We continued this encouragement and auditory stimulation for ten minutes until Josh made sustained contact with the paper (Reflexive Journal, week 11).
The process that Josh undertook herein was physically committed and undertaken fully independently. Josh began by sweeping the paper side to side in the way we had seen previously but now with a greater deal of emphasis, making it crumple and rustle as he did so. His head was low to the desk and he was following the sound with his right ear turned slightly downwards. He was entirely absorbed with this activity for few moments before drawing the paper towards his chest and upwards to his head in a strong pulling gesture. His face still low now meant that the paper was almost a loosely folded mask at the front and sides of his head (Process film; Photo thesis; Photograph 5 Working with Paper). Josh seemed fully absorbed by this process and began using his face to press very closely against the paper until it began to take on a bowled out form at one end, the opposite end retaining the marks of sustained compression by hand (Process film). I was astonished and delighted at how rapidly and with the degree of focus Josh had transformed the sheet of paper. I turned to Steve to express this and saw him shake his head to echo the same surprise and pleasure. The culmination of this new process was in the final pieces of artwork created in the session (Process film).

The unraveling of these first pieces of 3D led me to consider its potential to become a stronger sculptural material. By using a light PVA wash that would not dominate the main material yet stay open long enough for Josh to explore, I could see a way to retain the resulting form of the material. The resulting geometric sculptures, like origami pieces, could be traced in reverse, as the folds remained loose enough for their chronology to be understood and the order of their art-making re-enacted. They could then be understood as having a self-reflexive quality in terms of their process. Using deep listening with Josh meant responding by providing a more malleable material that would both capture and retain this new language of mark-making. This form of deep listening, viewed as a relational activity could be seen as Josh influencing his supporters to provide the artistic, material input to meet his developing process. Josh's creation of the brown paper sculptures can be thought of as mark-making that is both touch and sound-response, the paper providing both auditory and tactile impetus for exploration: the resulting works as sculptural-sound pieces.
Conditions and Barriers to Meaningful Engagement

The data showed that there were a number of key factors providing an integrated environment that seemed likely to be supporting Josh in making his artworks, and that these provided pathways into critical clusters of meaningful activity. Factors included sound and physical stimulation alongside the involvement of key staff and friends, and new experiences linked to art materials. Sometimes practitioners making interventions will need to utilise what is available in the room in order to meet a person where they are or in the ways they are accustomed to because of the particular support they have been receiving. Staff were resolved that the space hopper they had been using to stimulate Josh was a firm favourite of his; during the project it became clear that beyond this it was a valid tool to support the facilitation of his art-making. The data showed that Josh’s space hopper could be relied on fairly systematically to engage him specifically by directing his focus to the people and materials in front of him; it was most frequently the specific tool that provided the stimulation to Josh to smile and laugh, and thereby directly increased his enjoyment of
the sessions. It can therefore be said that the space hopper was a condition to Josh's meaningful engagement in the participatory arts setting.

An established relationship was critical to the development of this deeper empathy with Josh. As the practice of deep listening developed in staff and myself and as we became more sensitised to the direction Josh’s art-making was taking, sessions became necessarily increasingly flexible. This elasticity in the facilitation was critical so that we could respond to his courage and curiosity and maximise the opportunities he was seeking. Supporters then, embodied some of the key conditions needed for Josh to engage meaningfully in their cultivating characteristics such as flexibility, deep listening and sensitisation to his preferences. It was evident that some staff were able to acquire these skills to a greater or lesser degree, and that sometimes barriers were present.

Steve was extremely receptive to the ideas and approaches held in the project. He worked regularly with Josh outside of the sessions and had a very good understanding of his communication style. His empathetic relationship with Josh meant that it was not a surprise that he was present at both of the MA moments described here. Conversely, another member of the care team, Julie, supported Josh in other sessions and articulated both a reluctance and occasionally confusion about how engage with the facilitation approach being used. In week 8, film data shows Julie sitting next to Josh, she is engaged with talking to him but his materials remain out of reach on the table. In the sessions where Julie was supporting Josh, the conditions for meaningful engagement were only achieved when I was able to join their table. Outside of that I noticed Julie’s preference for focusing on practical care related tasks. It is clear that empathetic relationships, staff buy-in and staff support were conditions for meaningful engagement in this setting with Josh.

**Case Study 7 – Sharon**

This case study will look at the evolution of a single meaningful activity (MA) over an extended timeframe and through a thick description after Denzin and Lopez. In order to establish the MA, I draw on the events leading to and away from it and in doing so notice how Sharon’s established preferences for a pre-established enthusiasm evolve into an understanding of this as a creative activity. The chapter concludes by gathering together the data to describe the conditions for meaningful engagement in the context of this study.
The data collected in relation to Sharon proved very helpful for investigating her relationships with the materials and supporters in the workshops; in particular the GoPro camera footage enabled myself and care staff to see these from her perspective. The Process Film developed from this and other film footage, and housed on the CD that accompanies this written part of the thesis, should be viewed as part of the thick description for this case. As with all case studies, the network view function of Atlas.ti enabled an examination of key data including staff post session questionnaires, capacity and consent data, triangulation sessions, my research journal and Sharon’s edited Diana book. This view supports the compression and expansion of the data, giving it form and thereby enabling representation of findings as visual maps with connections, relationships, clusters and patterns.

*Meaningful Activity*

During the capacity assessment and consent processes of the project, Jane, a member of the care team, told me that Sharon had a keen interest in a particular book about Princess Diana; she had been looking through the book with the staff in her one-on-one sessions at the centre. This hardback coffee table book was one that celebrated Diana's life through high quality, colour photographic images; its pages were large and formatted in a landscape position. I asked why this book was of interest and Jane responded, “she just likes it because she really loves Diana, she loves looking at pictures of her and watching her on the TV.” Jane had added that Sharon had been reading the book for a while, a few months now at least. I learned that despite other offerings she had been interested only in this one book, refusing to look at any others.

Academic research has positioned shared reading as a participatory arts activity given its “inclusiveness; even people who cannot read…can participate meaningfully” (Billington et al. 27) and so Sharon’s preference offered a logical starting point for the weekly participatory workshops. When Sharon arrived to the dining room in the morning she would navigate her wheelchair to the same place, near the back of the room in the proximity of the cooker, fridge and kettle. Sharon did not enjoy interacting with others in the space and had historically been supported on a one-on-one basis; she turned away if approached by anyone other than her usual carer. She asked her carer for tea immediately upon arrival,
“tea, tea, tea!” and once settled with her usual cup, began to look for Diana though the emphatic repetition of the word “book” until its delivery (Micro Analysis Notes: Week 3, Week 4, Week 6, Week 8). I saw that whilst we understood Sharon’s interest in looking through the book, her engagement was not understood beyond this simple assessment; it became evident that there were conflicting perceptions about her continued interaction with it.

My journal notes a conversation with one of the Seniors who had stopped me outside the dining room after a workshop one day: “there is a bit of concern at a higher level about Sharon using the Diana book in her sessions. They think it might be holding her back and want to get her away from using it” (Reflexive Journal, Week 8). I could not get clarification from the Senior on where these concerns were coming from so went to speak to Janice, the Manager. I noted later that she “did not seem to understand this or particularly agree” (Journal, Week 8). Although this follow-up conversation with Janice did not add any weight to these possible misgivings, the PAR approach to research commits the researcher to continue hearing the voices of those involved in the study as its “practices are constituted in social interaction” (Kemmis and McTaggart 281).

Indeed, through the PAR method I was reminded of the complexity of both holding multiple points of view impacting on a study and working towards a collaboratively agreed direction of travel. “Participatory action research is practical and collaborative” (Kemmis and McTaggart 281). The touchstone for the direction we took however was that Sharon remain at the heart of these conversations, her opinions and experiences leading the research by showing us starting points and paths to follow. My tool for following Sharon’s lead was an approach to listening that was not only imaginative and creatively responsive, but also highly attuned to her communications in order to properly execute rolling consent. I had learned through Sharon’s capacity assessment that she did not like to touch or hold objects and felt that her willingness to repeatedly physically interact with the Diana book was important in our assessment of its future use. My approach was to develop deep listening: a set of actions collectively matured with the input of care staff, family members and most critically, participants. The cultivation of deep listening proved valuable in the first eight weeks of data-collection where a picture began to grow of how Sharon might be interacting with the book.
Data analysis around the choices Sharon made in this eight week period show a mixed picture of interaction with paint, paper and the iPAd: she used a paint brush, paint and paper for a short period in Sessions 1 and 6, pencils and paper in Sessions 6 and 7 and chose not to interact with the iPAd or use the paint in Sessions 5 and 6. In Session 3, my data notes and the accompanying triangulation session with staff show that Sharon refused paint but was interested in the Diana images. It was agreed by the five staff gathered in a room at the Centre that Sharon had stated, "book, book" when offered paint and paper (Triangulation Session Notes, Week 3). In Sessions 5 to 8, Julie, Sharon’s carer, and I checked if Sharon would look at a different book, one of which was a new book about Diana. At different times during the first three sessions we noted that Sharon consistently chose the old Diana book but in week 8 she asked for the new Diana book. I reflected with Julie that she was "reading her new book in a concentrated way and choosing to continue reading" (Micro Analysis Book, Week 8). Two common threads in the data emerged from this period in the workshops onwards: the continued interest in, and requests for, the new Diana book, and a developing interest in filming herself using the GoPro camera (Process film).

It was towards the end of this first 8-week period that I began to develop a finer attunement to Sharon’s communication style and preferences. This is clear in images both of mirroring, evidencing our developing rapport (Photo thesis), and of Sharon leading the development of her process (Process film). Three areas of the data supported my surfacing ideas on what might constitute meaningful engagement for Sharon: the cluster of reliable verbal and nonverbal communication Sharon was using, her utilisation of the GoPro and what this revealed in terms of our ability to see the world from her perspective, and the social and supportive interaction by staff working with Sharon. The latter was in terms of her integration into the group and the development of her creative process. The workshops showed that Sharon was tapping particular pages of the books and often accompanying these taps with a small assembly of words, in particular “who’s that?” and “book.” The perception from staff was that interaction with the book was consistently engaging, regularly meaningful and always preferred over other activity (Network view 1; Process film). Drawing on Straus’ notion of fixity of focus which describes the style of autistic artists as doing “one single thing with great intensity again and again” (468), I found a useful lens through which to view Sharon’s approach to interacting with her book. I spoke to Kelly, Harriett and Julie who had been working with Sharon: “do you think Sharon likes any
pages in the Diana book especially?” Kelly looked thoughtful, “yeah she always stops on that big wedding photo picture, the one on two pages, and taps it.” The others agreed that they had seen Sharon tap the same page, and noted other pages that were receiving the same attention: “I noticed Sharon would stop at page 65 and look at that page for a long time.” I said to them, “I’ve noticed that. I’ve been thinking I need to consider that it is the book that might be meaningful, and develop a line of enquiry about in what ways this could be. I want to see if there is a pattern” (Research Journal, Week 7).

Rather than simply accepting a position on the use of the book that could indicate entrenched inequalities in the day service itself, I drew on the self-empowerment processes proposed by Friere’s conscientisation (174) as a means of decoding the nature of Sharon’s activity. Although there were limitations in the ways that Sharon could participate in the process as Friere defines it, it seemed that participatory video would able to support her to “give voice” to her interests (Rojas and Sanahuja 32). I talked to Julie and we agreed that Sharon might be receptive to the introduction of a GoPro camera in her workspace. I had conceived of the camera as a methodological resource that would illuminate Sharon’s views, efforts and points of focus and hoped these new perspectives would influence and inform her key supporters. When Sharon assented to wearing the GoPro on a chest harness (Process film) this came through her familiarisation with it by sight via the slow introduction to her workspace: I attached it first to the back of her chair and later mounted in on the table in front of her. Gaining access to Sharon’s point of view was a key milestone in the understanding of what constituted her meaningful engagement.

What became clear through observation of the data from Sharon’s perspective was the physical effort, tenacity, patience and focus it took her to engage with the book (Process Film). I was both enthralled and humbled upon viewing the GoPro data for the first time and when I was able to share it in our next data triangulation session, staff became emotional. Harriett put our collective thoughts into words: “she’s working so hard to turn those pages, I know we always see her doing that but I didn't realise how much effort it took”; we all nodded and she went on, “she is definitely stopping on the same pages!” I was really beginning to think that there might a discernible pattern to this so I suggested we make this our goal. We chatted about how we could record the pages that Sharon was stopping on and agreed that we needed something simple and nonintrusive that would not make turning the pages harder for Sharon. We agreed on small, thin sticky Post-its applied
to the edge of the page each time Sharon stopped on it. These would have the week pre-written on them. In this way, over the next thirteen weeks and with the aid of the GoPro, we recorded the pages that Sharon stopped on to tap and comment (Process film).

It was clear that Sharon was indeed choosing to point out specific book pages (Network View Appendix G) and that the images therein had particular features. Chosen images had a characteristic palette of red, black and white and all were close-ups of Diana’s face or collages of her. Very few images had other people in them except the large wedding photo and one with the young princes. This led me to understand Sharon’s activity as one beyond simply reading. Sharon was selecting and commenting on the source material and in this, establishing a pattern of preference that represented a systematic condensing and therefore modification of it. Seen from Sharon’s perspective, I recognised her interaction with the book as editing (Network View Appendix G). Towards the end of the workshop period I noticed that this editing practice was expanding into a tool to communicate with other participants and that by week 20, Sharon was relaxed enough to share both her process and a smile (Photograph 6 Sharing Process).

Photograph 6 ‘Sharing Process’
Melaneia Warwick  Original in Colour
Meaningful Engagement

When Sharon first attended the workshops she had been used to working alone on a table without other service users at it. Week 20 presented an important watershed in that it was the first time Sharon showed us real enjoyment of her new social conditions; of her bravery and curiosity there can be no doubt. My goals to magnify competence whilst attempting to democratise research practices had been full of tensions, were highly intensive and in places, faltering. It is not possible to cleave away the potential impact of the new setting from Sharon’s willingness to explore different materials, yet by following her lead, we were able to distinguish new ways of recognising her reading experience. It was evident though that week 20 also revealed starting points, and that more time was needed to begin to build on the editing practice and new confidence that Sharon had developed.

Unraveling meaningful engagement meant deciphering Sharon’s approach to the material objects she preferred to engage with, and translating this to key supporters. It also involved looking closely at Sharon’s determination to stay in the busy workshop space and ultimately develop the confidence to comfortably engage with another participant. Mansell and Beadle-Brown (40-45) emphasise supporting people to move away from objects or activities that might simply comfort, enable them to retreat or avoid new experiences. Instead, they say that supporters should devote more energy to encouraging people to relinquish activities where they may continue to choose the familiar because they do not know how to do so otherwise. Their case for active support is very much tied to the domestic and social contexts of a person with PMLD, but the participatory arts intersect these models of support often as interventions outside of established routines. Through our better understanding of Sharon’s interaction with her preferred materials, she showed us her "claim on the arts" (Belfiore and Bennett 195). In sharing her experiences it became clear that viewing them literally from her point of view was very powerful and developed support for this from her audience of key supporters (Data Triangulation, Session 3). Through the mechanism of deep listening, I understood Sharon’s editing practice as useful in giving voice and modifying the behaviour of key people (Photo thesis). In short, Sharon was the creative protagonist of her own support community.

It took a number of parties to co-negotiate the midwifery of what became to be understood as ME for Sharon. At the end of the workshops we noted how meaningful Sharon’s
relationship with Hayley had become, indeed “the extent to which people with severe and profound intellectual disabilities are supported to engage in social relationships is just as important as their engagement in any task” (Mansell and Beadle-Brown 46). Conditions for Sharon’s ME within the context of this study were time, enthusiastic and interested care staff, deep listening and support to engage in social relationships; there is no doubt that she had a real passion for books and that there was a tangible focus and interest in the distinct details of these.

Overarching Case Studies

Introduction

In the context of this doctoral study, meaningful engagement (ME) and meaningful activity (MA) were interlinked aspects of a sustained creative intervention that brought a group of adults into a new social group. Framing the creative workshops were a number of environmental, ethical and practice-led assumptions, conditions and approaches; patterns of consistency in these were understood to provide the broader ME terrain. These were established as conditions and principles that could be replicated and tested by artist and care practitioners; they are listed and discussed under Lists 1 and 2 (159; 160). Close attention was also given to the shape of case-specific factors and noted within individual case analysis. An understanding of MA was gained by way of an evolving attunement to participant visual vocabularies as these developed through interactions with arts materials.

Visual vocabularies were personal, singular and identifiable; they consisted of the marks participants made visible through gesture or application of energy with, through or onto creative material and tools. The language of mark-making was realised through the workshops via lines, dots, dashes, smudges, smears and scrapes, emphatic splashes and tentative pressing. Individual personal vocabularies provided a lens through which to ascertain moments of particular intensity, bravery, playfulness and courage. In the modulation of material interaction, such moments evidenced a spike that was different enough from other events to be considered distinct. Sometimes such spikes were the culmination of a participant moving towards material such as Rob making sustained contact with compressed charcoal after many weeks of fleeting touches that were characterised by his movements away. When Katherine began to splash paint and water
across her canvas this was within an hour of new, bold and highly gestural mark-making that was the culmination of weeks of increasingly brave interactions with material. Katherine’s splattering marked the beginning of an intense peak of activity that was repeated in future sessions. This quality of engagement was also seen in Hayley’s taking up of the film camera; in her intense focus and newfound playfulness. Hayley’s first filming activity clearly evidenced a new creative way making, a visual vocabulary characterised by the choices she made when editing in her experiences.

MAs were distinguished by their intensity: they appeared where a participant’s creative conversation had spiked. They represented a turning point that was witnessed through material or other creative events. In a model of ME, the points of MA would be viewed as triangular peaks connected by a forward moving, sometimes repetitive, line of activity. Each of the cases in the study presented these ridge lines differently, when repetitive they had switchback roads that traversed their particular terrain; all had peaks and were boundaried by the ME conditions and principles discussed.

This overarching analysis of the case studies brings together the set of principles and conditions for ME Both principles and conditions were echoed in the codes that grew out of the study. Whilst a small number of codes were assigned pre-data-collection, the rest were allowed to collaboratively emerge during the workshops and triangulated with staff input and ideas. I recognised the complexities of interpretive analysis in usefully separating and reorganising data in order to access the meanings participants were assigning to them. In order to better enable me to manage the large quantity of data I had collected, I identified a hierarchy of codes (Table 4). This was developed by organising codes into deductive and inductive sections and then listing the top level or broad codes along the left hand column; I created a description next to these that included a number of code elements I then reached a consolidated view of these through their reorganising into a smaller number of thematic groups that became the conditions that support ME (List 2). Deductive codes emerged from the literature; I started data analysis with these. Inductive codes were generated through close exploration of the film, photographic, questionnaire and Dictaphone data.
<table>
<thead>
<tr>
<th>Major Category</th>
<th>Associated Concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Choice</strong></td>
<td>Making a clear, independent selection from a number of alternatives, which are limited in scale and scope for the purposes of this study. Includes not selecting any option. In the moment identifiable factors that impact on the development of the participant’s art making process. The mechanism by which preferences are elected.</td>
</tr>
<tr>
<td><strong>Preference</strong></td>
<td>Consistently elected option already known to the support infrastructure.</td>
</tr>
<tr>
<td><strong>Assent / Dissent</strong></td>
<td>A form of in the moment agreement / disagreement. Assent assumes a lower level of information assimilation, voluntariness and decision-making than that of consent. Emotional, social and physical cues. Supports developing meaning behind participant behaviours and respects a limited or developing autonomy thereby contributing to self-determination.</td>
</tr>
<tr>
<td><strong>Unclear</strong></td>
<td>Unclear choice, preference, assent or dissent position; no consistent agreement from researcher and / or staff on what a participant wishes to communicate. The unclear code may present a moment of confusion and highlight where further thinking, reflection or enquiry are needed on the part of the researcher and / or staff.</td>
</tr>
</tbody>
</table>

**Emerging Codes.**
<table>
<thead>
<tr>
<th>Major Category</th>
<th>Associated Concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care issues</td>
<td>New untrained staff joining workshops due to a lack of trained staff being available because of sickness or performing other duties, different ratio of staff to participant than expected.</td>
</tr>
<tr>
<td>Staff motivation</td>
<td>Staff buy in or otherwise to approach to art making. Includes fear, reluctance, excuse making, negative perception of workshops, lack of understanding of approach, projecting previous negative experiences of self / participant, building on previous positive experiences of self / participant. Also inertia, lack of focus, positive encouragement, working with participatory approaches to support art making, sharing and showing participant’s work, advocating for participant.</td>
</tr>
<tr>
<td>Relationships</td>
<td>The nature of the relationship between staff and participant, researcher and participant, research and staff; participant-to-participant relationships in terms of importance, quality and impact. Where relationships might support or create barriers to a participant’s self-determination including mutual training &amp; sharing between researcher and staff in the workshop setting. Examples of mirroring and attentive listening are included within this code.</td>
</tr>
<tr>
<td>Creative process</td>
<td>Emerging actions used to interact and / or make connections with the art materials. An established or new way of a participant deciding when it is time to stop working with materials. Sharing and showing work to others, expressing a desire to work. Environmental factors that support making such as preferred sensory objects, tables or locations for working, going outside of the art making space, light, sounds. Participant gaining familiarity with tools and materials, problem solving. Competence and productivity in making; ownership.</td>
</tr>
</tbody>
</table>
Meaningful Activity A new experience that is enjoyed or engaged in with sustained focus. New materials and ways of working. Something articulated that has not been done so before, something new that marks a shift, growth or new stage. Self-determination seen in the artwork made or the creative endeavour undertaken and noted as significant by researcher and team. Participant defying previously held or limiting perceptions.

Context

The data-collection sessions took place in the dining room at New Road Day Centre; the Centre was being run by Portsmouth City Council as part of their Day Service provision. The dining room was a large space with access to a garden via two sets of French doors. There was a good deal of light via these doors and windows and the room had a small sink and plenty of tables and chairs. The sink was utilised for the art sessions and facilitated food breaks. The room was designated for the sessions but did not have a closed-door policy; it was often utilised in the early part of the sessions when tea and coffee was enjoyed as part of the morning routine. Although service users had dedicated one to one support occasionally someone came into the space alone.

This practice-led study brought me together with care staff group who acting as creative-enablers, delivered participatory arts workshops for adults with PMLD. From the principles noted in List 1, numbers 3, 4 and 8 were bought to the study from my set of previously developed working methods. As these and new working methods grew organically through the user-led workshops - in that they were informed by participants' moment-to-moment interaction with their environment - new principles germinated and established ones developed. Whilst the case studies are all unique these principles represented a unifying set of approaches needed to support ME. Additional to these principles a set of environmental conditions were identified as positively contributing to, and creating barriers for meaningful activities (MAs) to occur. The MAs were identified as concrete evidence of a unique development in participants' evolving creative processes.
Participatory Arts Principles

The principles outlined here can be thought of as mechanisms for the delivery and organisation of the various elements of participatory arts workshops for the context of this doctoral study.

List 1 Participatory Arts Principles for Creative-Enablers

1. Develop a practical ethical framework
2. Share skills and expertise to establish trust, confidence and knowledge
3. Individualise artist quality materials and tools
4. Emphasise participant independence
5. Take safe risks
6. Utilise deep listening
7. Practice cheerleading
8. Triangulate with supporters

Repeated inquiry saw new intersections and separations ebb and flow out of a complex data set consisting of film, photography, audio, books, questionnaires, supporting documents to establish capacity and consent, and my research journal. Each of the case studies examined in this thesis were analysed in a data field characterised by an extended perspective both in terms of chronology and critical MA moments. This enabled enquiries into the data to be viewed interchangeably: a macro perspective developed in Atlas.ti allowed the researcher to *hold* various moments at one time for exploration, moving freely between them by way of the visual networks created in the software. Scale, scope and relationships were manipulated within networks enabling shifts in focus that facilitated further questions to be asked. It was important that the conditions that steered the MAs be seen in this expanded view in order to support participants to gain familiarity with the research context, tools and materials. Notably, the data supports this approach showing peaks in MAs at weeks 8, 10 and 20 (Micro Analysis, Weeks 8, 10, 20).
Conditions for ME were realised according to their frequency across the cases and are noted in List 2 in numerical order. Numbering reflects the quantity of cases in which the condition was seen as opposed to the number of times the condition was seen.

**List 2  Conditions that support Meaningful Engagement**

1. An informed base-line position about each participant
2. Continued in-workshop training for care staff
3. Open and honest sharing of ideas with care staff, managers and supporters
4. Developing creative opportunities delivered at a participant-led pace
5. A consistent group of care staff
6. Artist quality materials and professional equipment
7. A social setting with dedicated, individualised work areas
8. 3-hour workshops delivered across a sustained period of weeks
9. Participation in workshops remains available where health and other challenges compromise regular attendance

**Discussion**

In practice, the principle of establishing a practical ethical framework included gaining NHS ethics approval for the study, following best practice in capacity assessments and gaining best interest or informed consent to participate via well-written forms. Whilst presenting a major administrative burden that was not always a good fit for the participatory arts, gaining NHS ethical approval acted as an assurance passport for supporters and staff in the context of day services. Specifically, it enabled trust to be developed where the participatory arts were not recognised, appreciated or understood and as such supported the ethical framework of the study. My Reflexive Journal notes, “In a chat with a couple of the mums at reception, someone had commented that they didn’t know about art but were pleased I had ethical approval as it made them feel confident in me” (May, 2014). Once the workshops commenced, an ethical framework was practically maintained through
establishing rolling consent from the research participants. This was triangulated (Principle 8) through frequent checks with them, myself, care staff and other supporters both inside and outside of the workshop space and supported when meaningful conditions 3 and 5 were in place. The absence of these as seen in the case of Rob created disruption and delays to the development of his creative process through the need for this narrative to be frequent relayed to new staff members (ME Condition 2). Despite these challenges the importance of retaining Rob’s place in the study led to his progress in the study as triangulated by his key supporters (ME Condition 9).

Buy-in was important to the study, both at an organisational and staff level in order to develop a platform for trust, skills and knowledge between myself and care staff in a short space of time (Principle 2). Early into the study I noted:

What struck me repeatedly before, during and after the session was how critical staff attitudes would be to enable the participants to access the arts as fully as possible. Staff members can be awkward, shy, have very little experience of the arts, or none at all, hold strong or unclear ideas about what participants can or cannot do. They may be fearful to try new approaches themselves and this may affect their ability to support people to take risks. Alternatively they may be playful, positive, optimistic, and believe that risk is possible for people. Values and attitudes are critical to the success of this work (Week 1).

Gaining buy-in involved opening up early opportunities for day services staff to develop understanding of research issues, discuss information gathering techniques and understand the potential of art materials through experiential learning exercises (ME Conditions 2 and 3). In this way the data-collection for this doctoral study began with a coming together of researcher and staff, which privileged the sharing of expertise and the establishment of an early basis for trust. Practical application of this within the workshop settings was via a cyclical pattern of support that aided participant independence: staff assisted participants and were in turn guided by me. I worked directly with participants and whilst doing so gained important information from staff. In this I supported care staff whilst they worked with participants, sometimes drawing on conversations conducted with the day centre management team outside of the room (Principle 4; ME Condition 4). In the case of Sharon, conversations with Seniors and Managers took place about her preferred objects, which led to my supporting her to wear a GoPro camera. This was the tool that helped to illuminate Sharon’s book activity beyond simple reading.
Workshops were positioned at the participatory end of the Audience Involvement Spectrum where the "artistic outcome is uncertain and largely in the hands of the participants (James Irvine Foundation 15). Within their practical framework, workshops enabled a radical site for participant independence via knowledge production underpinned by reciprocal patterns of support. In their bringing together of previously separated day centre users, they privileged human connection (ME Conditions 7 and 8; Principle 3) and in doing so aligned to Matarasso’s critique of mainstream understandings of art. In his discussion of this in terms of the performing arts, Goodley and Moore assert, “(Matarasso’s critique) makes it possible to embrace those arts that take as their starting point the ‘untrained’ actions of ‘novice’ performers” and to this I add other categories of novice artists including visual artists (14). A participant-led approach meant that in our practice of deep listening (Principle 6), each directed the research team towards their interests and preferences. Carefully attuning to Hayley’s discomfort at being filmed led to a radical turning of the political gaze on its head; in her application of deep listening, carer Kelly catalysed a new, pivotal direction in Dani’s making.

In the ensuing model of triangulation, staff and myself worked together to reflect on how best to support participants’ creative evolution. Patterns of support modulated: there were sudden shifts in proximity from members the research team towards the participant in order to maintain the moment to moment connection necessary to facilitate a new creative pathway or MA, usually supported by cheerleading (Principles 5 and 7). At other times I would move positions with a carer who was facilitating a participant in order to model clarity, sensitivity or how we might promote further independence (Principles 4 and 5). In order to ensure the integrity of the research findings staff were invited to come together for monthly data checking. Here film data would be reviewed through my open questions aimed at ascertaining the validity of growing assumptions about preferences, barriers and relationships. The principle of triangulation emphasised reciprocity of ideas by encouraging staff input and reinforcing the importance of their knowledge of participants (Principles 7 and 8). Indeed this principle reflects the construction of PAR research as a "social interaction" (Kemmis and McTaggart 281). Triangulation also occurred spontaneously in the forms of fact checking, corridor conversations and via the evaluation forms that care staff completed at the end of each session. All of this enabled a foundation of competence to be developed in the study bolstering confidence of staff. I noted this in Week 6 when reflecting on the input I had been giving to a member of staff, Jane to work with Sharon, “J
The importance of the quality and agency of artistic materials has been highlighted within this thesis: materials that retained marks well, with clarity and offered sensory stimulation were utilised with the intention of reflecting established and developing preferences. This responsive approach is one that Adams emphasises as important to this particular constituency, “….the context of people’s lives and what they experience has to be addressed as moment by moment, observational and responsive methodology” (Fox and Macpherson 158; ME Conditions 6 and 7; Principle 3). These and professional tools such as GoPro and HD cameras supported the research team to identify current positions participants held regarding material and object preferences. In some cases through these, work could be done that enabled pathways to MAs to be created (Case Study Josh; Case Study Sharon). The use of participatory film making methods attempted to disrupt the disabling experience of the gaze with the aim of transforming participants into agents. These methods privileged participant experience in the workshops beyond a “merely attendance level” (Rojas and Sanajuha 32), and in doing so enabled us question assumptions on when, how and why we might introduce safe risk as an adjustment to in-progress approaches; in short how we might be led by the experiences of the participant.

This study set out to engage with and investigate, the notion of meaningful engagement for people with PMLD as initially posited within Mansell and Beadle-Brown’s landmark model of person-centred active support. This model emphasised a direction of travel that focused on a person gaining control and independence, and developing relationships. It did this within the framework of domestic activity. This doctoral study set out to extend the range of experience available to people, going beyond the familiar and the routine, working with staff to understand the artistic processes that participants were developing. This new range of experience went beyond the realm of simple leisure pursuits such as watching TV or making cards consequently extending the range of professional encounters that care staff had experienced. In this the study engendered staff buy-in, confidence and skills development; staff had fun and gained empathy for the experiences that participants were
having. Their evaluation forms reinforced this as discussed in the individual case study analysis.

The workshops developed the opportunities that people with PMLD had to share the same space as others; they did so in part, by employing materials that had the flexibility and potential to absorb, engage, amuse and comfort. Not all participants had shared a space with others; rather they had received 1-1 support and were deemed to be unable to sit comfortably in a room with other service users. Whilst the 1-1 support they had received was tailored to their needs, they were not able to develop their social skills and friendships as readily as they otherwise might. By elevating the social situation beyond the domestic and the familiar through material opportunities and working approaches that embraced a long view, this study enabled initially reluctant participants to sit together and share their creative processes. In one case this occurred in week 19, serving as a reminder of how important extended temporal boundaries were; had we 'given up' due to other expectations of 'success' the outcomes might have been very different. More importantly the approach I was emphasising meant that we had to really consider what might be meaningful socially for someone and that this could change. This approach made space within traditional expectations on what, how and when a person might build new skills and experiences in their contact with others.

In totality the principles discussed achieved individuated participatory arts pathways. They were forged through a practice of deep and expansive forms of listening, observing and watching that enabled myself and care staff to notice the emerging individual aspects of each participant's creative practice. These pathways were nuanced in each case, influenced by a set of identified conditions for ME.
Chapter 7

Conclusion

Research questions

This doctoral study investigated one main research question, a discussion of this is developed in this concluding chapter:

1. How can adults with profound and multiple learning disabilities (PMLD) engaging in participatory arts workshops inform an understanding of meaningful engagement in this context?

The participatory arts approaches initially developed within this study were based on the known preferences of each participant and further formed through their subsequent individual material, social and relational choices within the workshops. These positions were triangulated with care staff and other key supporters with a careful eye on rolling consent being maintained; the combination of these factors contributed to the conditions for ME recognised for each participant. In addition to the 8 frequently occurring ME conditions identified within this study, 10 principles for working with participatory arts were identified. The combination of principles and conditions identified what was perceived as meaningful about the engagement people were involved in, as well as the ways in which ME was supported by myself and staff in the inclusive arts setting. They further illuminated an understanding of the specific processes that were commonly utilised in order to facilitate this arts intervention. Both conditions and principles were established within a challenging environment of the dining room: there was always a hum of activity with sudden shouts, laughter, scraping of chairs, clatter of cups and saucers, voices of staff, myself and the occasional unexpected visitor.

Dewey defines fulfillment as a completed experience and identifies the arts as a domain that allows for this to happen (98). In all cases where MAs were identified, echoes of processes seen in the meaningful activities described ripple out, reappearing deeper into the project. The data-collection period meant that the earlier meaningful activity moments were more sustained across the project. New approaches become integrated into
established processes for making. Examples from my study include Dani and Sharon engaging with new images in the forms of books using these as points of inspiration or developing their willingness to try new approaches where books were the tools. Kathryn gained independence by working on canvases and then at scale and Charlotte by working with both hands and then learning to use tools such as brushes and palette knives. Hayley took ownership of the HD camera to film her own creative practice resulting in her editing in of her experience. Josh's gains in confidence in using plant material led to his independent mark making with plants, and Rob's willingness to make contact with crushed charcoal supported the development of a series of 3D pieces. ME can be understood then, as a set of conditions that support MAs to take place by building creative opportunities and principles for delivery of these. ME is participant-led and as such responds to individual preferences and choices; it avoids the homogenisation of experience among people with PMLD (Nind *What is inclusive research?* 71).

Meaningful engagement within active support has been positioned as a goal for engaging people with PMLD in their domestic and social settings through deeper involvement in their daily tasks. Through concrete rationales and principles, active support provided a research-based guide to those providing care or making decisions about the care to be provided. Whilst this service-focussed model acknowledged the importance of quality of life factors indicators including relationships, self-concept, choices, self-direction and the importance of the quality of care a person received in terms of them *doing over passive observation*, it conceded that the term meaningful engagement was not fully realised. However, drivers for the inclusion of people with intellectual learning disabilities such as the UN *Convention of the Rights of Persons with Disabilities*, the progress report *Valuing People* and the report responding in terms of the PMLD population, *Raising our Sights* have emphasised the social, relational and recreational rights of this population. This study identified an intellectual problem in the lack of a concrete definition of meaningful engagement in the literature it intersected, and in the work that the participatory arts could usefully do with an adult population with PMLD. It set out to pin down the constituting essential features of meaningful engagement in relation to the visual arts as an intervention in a care setting. In cultivating opportunities for people to participate in the visual arts, this study has responded to Mansell and Beadle-Brown’s call for further research in what might be thought of as ‘leisure services’ (181). In this it has contributed to the literature by fleshing out this critically important if “rather simple, even crude idea”
(Mansell and Beadle-Brown 40) by developing an understanding of local outcomes into best practice processes and approaches with the aim of impacting on a broad audience nationally to affect a better understanding of how we might work more effectively with people with PMLD.

Considered together, the conditions and principles outlined in this study indicate the forms that meaningful engagement could take and through which facilitation of meaningful activity for individuals could occur, reflecting important moments of growth or development. This thesis makes its distinctive contribution to the fields of participatory arts and intellectual disability studies; it develops inclusive research practices for working with PMLD populations by bringing to light new methods by which visual methodologies can be articulated alongside ethical regulations in research.

Application to wider debate

This thesis outlines a practice-led investigation into understanding what was meaningful to those participating in the study; it explored the activities that occurred at the participant led end of an expanded field of relational arts practices (James Irvine Foundation, 2014). Art was used as the pathway because it provided a unique, flexible, social and personal space that had potential to develop permanent artifacts and records of each participant's process of engagement. The study sought to reimagine a preexisting but fragmented community by introducing a communal space for some of those who otherwise received support in isolation. This enacting of Bourraird's art is the place that produces a specific sociability was carried out through the environmental conditions that supported the workshops, and reinforced by the opportunities afforded through the art materials themselves.

The utility of art in this way places this thesis in a highly debated area in the literature that contests what is sometimes perceived as the instrumentality of the arts. This "moralism" (Belfiore and Bennett 76) privileges the usefulness of the arts beyond an aesthetic outcome effectively reducing what is seen as their primary purpose. This seemingly dichotomous position blurs through approaches that, whilst socially engaged, place the professional artist in the role of artist visionary or collaborator. In such practices a position of moralism can be adopted whilst it remains clear that the professional artist provides a 'quality assurance' mechanism for the aesthetic outcome. What remains is a position that
the art practice undertaken would not be fully resolved without the inclusion of the creative voice of the professional artist.

This thesis intersects moralism and autonomism differently: the professional artist does not validate the aesthetic quality of the artworks created. Rather, through the application of a set of working principles, she provides material knowledge and develops key environmental conditions in order to co-create the conditions for independent art making to occur. In academic research, the infrastructure for intervention is a prior ethical engagement with the appropriate governance body in order to gain access to support settings and develop assurance for colleagues therein. Once in the workshop space, this ethical assurance manifests as rolling consent established in conversation with participants’ in-the-moment art making and the perceptions of care staff. In the context of this study the working imperative was for supporters to make focussed moves towards facilitating participants’ independent making. Here then moralism does not play second to aestheticism rather it sets up the conditions for people to discover their own artful, creative voices and ways of knowing (Fox and Macpherson 6).

Workshops were situated where they could best be accessed for participants and where strong connections with staff could be developed. In relocating making outside of the studio and into day services this intervention disrupted the "compartmental conception" (Dewey 6) of art placing its access directly into the lives and communities of people with PMLD. There was a distinct creative-enabling technique needed for each case as described in the case studies analysis. In order for the resulting approach to maximise the creative opportunities for participants there was a need to respond in the evolving environment, "Life goes on in an environment; not merely in it but because of it, through interaction with it" (Dewey 12). Through this evolution a model of collectivity was emphasised: the creative-enabler role was in readying and incubating the conditions for making to be such that participant authorship could be preserved. There was then, a collaborative intention to produce independent art making. Critically though, this model situated the responsibility for creative agency, which manifested as concrete object-production, a process for making or social exchange, with the PMLD artist.

The concept of independence is highly politicised for learning disabled people, as this is when the dominant social order is disrupted. Yet the arts offer opportunities for
participation and presentation, indeed, “It is time that this medium be open to all who have an ability which has been unnoticed in the shadow of society’ attitudes about disability” (Miller qtd. in Goodley “Learning Disability” 5). In carving out a space for people with PMLD to be valued on the basis of their art making processes I wanted to push against the boundaries of a traditional definition of aesthetics which is often linked to a conscious will to develop a creative outcome (Maclagan 63). This art can be experienced as potent materiality outside of traditional positions of artist as sole creator and audience as projectors of their own experiences. A person's willingness to respond to their environment and the art materials encountered there in-the-moment without a tangibly conscious desire to make an impactful piece of art should not disclude them from an audience. Indeed audience reactions to the art (this might include information on how the art was made) could be thought of as interactions with the work which co-create meaning.

In this interaction then, the ability of the viewer can and must be trusted in the construction of meaning (Maclagan 73). The methodology utilised in this doctoral study enabled activities radically different from those participants had previously encountered to be undertaken within a safe space. Although not addressing a specific political goal, the processes developed and their end results reveal participants who were seen to develop distinct creative practices via their developing autonomy. Rob and Josh transgressed conventional forms of material usage in the study: Rob teaching us how to think differently about compressed charcoal, a traditional drawing material and Josh, using petals and stems to make marks on paper, how to think differently about drawing. This research contends that there is a legacy aspect to the artwork processes created in terms of its sustainability that sees the researcher able to leave the workshops to continue, with the potential to reach back into them in an advisory capacity if invited.

The data showed that the art made or other creative expression of the seven individuals who participated in the project was not the same; where the same materials were used the final work exhibited their unique relationships to them. In this it reflected the emphasis on the use of quality artists materials that had the capacity to be responsive, retain and therefore aid articulation of the unique visual language of the artist. It was interesting to note that in the cases where mark making was the distinguishing creative approach, there was an echo of the working approaches of some modern artists. I was able to share images with care staff of the works of Eva Hesse, Jackson Pollock and Richard Serra that
were characterised by an unplanned method and where "spontaneous and un-thought forms" are legitimised (Maclagan 63). Despite these ‘professional’ parallels, the ineffability of the marks made is what resonated with the research team and key supporters. Whilst they could often not find the words to describe the processes undertaken and the final outcomes, they expressed joy, interest, surprise and affection for them.

**Methodological Recommendations**

**Practice-led Research**

This study views practice-led research as being concerned with the advancement of practice; it proposes that the learning from such research through practice has important consequences in and about such future practice. In the action-learning cycle within this study, a prolonged inquiry into a specific research question revealed knowledge about the governance of the investigation both practically and ethically. It is recommended that such an action-learning approach is used in future, similar studies in order to develop practice-led expertise.

**Ethical Approval**

Whilst presenting an administrative and time burden the process of obtaining valid capacity assessments and best interest or informed consent presented benefits. Through the careful organisation of meeting spaces, and a joined up approach with experienced professionals working alongside day services, conducting these sessions supported the sharing of vital information between participants, carers and myself. However, the culture of the IRAS form required by the NHS was firmly placed in the domains of scientific and medical research. As such it presented a number of barriers to the presentation of a creative research methodology; it was intellectually rigid in that it relied solely on text-based arguments, and it made demands that could not allow practice-led approaches to simply emerge. The lack of an opportunity to feedback to the NHS on its ethical approval process at any point in the lifecycle of the study created a vacuum in what might have been an important reflective opportunity. It is recommended that researchers continue to be courageous about undertaking NHS
ethics approval, and that they explore mechanisms for feeding back into this important process when undertaking practice-led research with this constituency.

Flow Diagram 1  Actions undertaken to gain NHS Ethical Approval and to comply with the Mental Capacity Act (2005).

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Data-collection and coding

The recommendation for this element of the methodology is to emphasise reliability through triangulation of data. This is crucial for studies that want to remain open to an exploratory nature but are also based on a model of establishing the rolling consent of participants. End-of-session staff questionnaires need to be well-written and would benefit from being supported by extrapolation of key experiences, perspectives and practical strategies, including how points of rolling consent were identified. These may be well supported through the addition of a discursive segment filmed at the end of each session,
perhaps by participants. This latter would benefit from the inclusion of recommendations for the following session.

This study raises important questions about the length of time the workshops were conducted over. Peaks in the data at around the half way and end points indicated critical turning points, assimilations of new processes, and key building points for social relationships. A longer study run across 40 weeks would test patterns in such advancements and assesses the extent to which they became established. This protracted data-collection phase analysis would be best supported by a smaller group of participants maximising the ability to gather deep data and to evaluate it against the emerging literature in this field. In such a demanding environment, a maximum group of three participants alongside their regular care staff would be merited. As discussed in the Methods and Research Design chapter the particular capabilities of the Atlas.ti software would provide a multi-faceted approach to managing the data collected that fits the primacy of the video data in this body of research.

Staff Development

Through the disposition of their social interaction, staff reinforced participant engagement in meaningful activity or passivity and inactivity, and by the feedback and reinforcement they provided. Because of this pivotal role there is a strong recommendation that development, sharing and in workshop training is received both prior to and throughout the data-collection phase. As discussed in the Methods and Research Design chapter staff should be supported to contribute to the triangulation of the data through the researcher cultivating attention to their expertise. Emphasis should also be placed on the sustainability of participatory arts approaches beyond the study.

The following table provides practical participatory arts considerations against ethical principles raised in the NHS IRAS application form.
### Table 5  Ethical principles mapped to participatory arts practice

<table>
<thead>
<tr>
<th>Ethical principle</th>
<th>Participatory arts practice</th>
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| 1. Avoid / minimise risk                               | 1.1 Keeping participants safe means developing ethical considerations for and alongside a range of stakeholders.  
|                                                        | 1.2 Stakeholders perception of risk may differ.  
|                                                        | 1.3 There may be a case for risk where risk is reconceptualised as an opportunity for access / engagement. |
| 2. Quality and integrity in research design            | 2.1 Where the research design involves input from participants how is this acknowledged?  
|                                                        | 2.2 What are the quality indicators for the project? Are these transparent to participants in ways that they can understand? |
| 3. Professional standards Good Code of Practice        | 3.1 Where the work involves collaborative making, being ethical involves knowing who owns what. |
| 4. Human participants should be ‘fully informed’       | 4.1 Being ethical includes conveying information appropriately to participants and their supporters.  
|                                                        | 4.2 Where the work involves collaborative making, bring ethical involves clarifying who owns what and for what purpose. |
| 5. Voluntary participation free from coercion           | 5.1 Being ethical means conveying the scope of the project and the anticipated participant role. This is often done through rigorously developed consent forms and information sheets but must be fit for purpose. |
| 6. Confidentiality maintained; privacy respected       | 6.1 Where work is multi-stakeholder being ethical means establishing agreement for using names, displaying artwork and establishing what, if any access there may be to research data and materials online. |
Practice Recommendations

Art Materials

Funding for activities in Day Services can be very low, these financial restrictions limiting choices that risk poor creative experiences. Cheap arts materials connote a lack of quality in arts based projects magnifying the limited opportunities for people with PMLD. In this doctoral study I did not wish to resort to the child centric, poor quality poster paints, glitter and colouring books often found in such settings. In addition any decision around material choice had to account for an NHS ethical requirement to minimise harm (IRAS Form, 2013). It is recommended for future studies investment in bulk quantities of good quality artist materials from suppliers such as Seawhites of Brighton should be made; researchers working with PMLD constituencies should request toxicity leaflets from suppliers.

Films about Process

This study raises questions about the ways in which creative research with PMLD populations is disseminated whilst maintaining ethical compliance. It is recommended that outcomes of research that aim to illustrate the processes developed by participants, are shared with the research community and key supporters through a web-site about the research practice which is password protected or has password protected areas. In cases where computer or internet access is not available or where a supporter wishes to enable a person to share the research practice, a photographic book can be developed to make the practice accessible.

Unexpected guests

A potential difficulty that can arise from delivering participatory arts in communal settings is the presence of service users who are not participating in the workshops. This was a common experience in the study sometimes becoming a distraction for participants, and requiring contingencies to be put in place. Future researchers are advised to ascertain and where possible agree access patterns to communal spaces. When access cannot be restricted, pre-emptive conversations are recommended for those working with visitors who might who present an unwanted interruption or make it difficult for the researcher to
direct the workshop as planned. Consensus points and strategies should be reached through these in order to maintain safe working practices for all involved.

*Reflexivity and Emotions*

A significant issue that could arise during the data-collection and analysis period is that of researcher emotions, which could become heightened, or overwhelming. Workshops can be challenging spaces to conduct research in; they are complex and noisy and the researcher is often called upon to solve problems neutrally and to think of the needs of all others in the room. Micro-analysis of film and photographic data can trigger profound memories particularly when participants are very unwell. There should be time to reflect following workshops, debriefing to the supervisors or having a mentor all provide models of support for the researcher. This can also contribute to shared learning among the research team.

*Power Relationships*

Developing relationships with participants will be a crucial aspect of a participatory arts study; often this will grow over a number of encounters and careful consideration needs to be given to the implications of this with reference to the balance of power between researcher and participants. Although participatory research may look to minimise power imbalances, there is a risk that the researcher could be perceived as the sole owner of expert knowledge. Focus should be on a participant-led study that distributes the emphasis of power through an epistemological position that knowledge is co-created and co-owned in different but equal ways by it authors.

*Concluding Comments*

*Policy Context and Transferability*

The influential Mansell report *Raising our Sights* (2010) investigated the provision of services for people with PMLD and made two recommendations under its investigation of employment and day opportunities. These outlined the need for people to "be able to take part in a wide range of meaningful activities" (29) and encouraged local authorities to
provide “a base from which adults with profound intellectual and multiple disabilities can go to different activities during the day…(which could)… provide more opportunities for social interaction” (29). Further pivotal work by Mansell and Beadle-Brown developed a description of Active Support and guidelines for its successful implementation, acknowledging that further research was needed on its implementation outside of the domestic context (181). This study builds on this and the Raising our Sights recommendations by investigating what these 'meaningful activities' might mean from the experiences and viewpoints of people with PMLD. It does so through the practice of participatory arts and in this way it informs the meaningful engagement agenda in unique and new ways. Insights were gained by starting with established ways of working with the 7 participants while being led by their new approaches.

The conditions and principles for ME outlined in this study provide useful practical framework and a set of concepts for future researchers and policy-makers in this area. Policy makers working with the agenda for meaningful engagement are encouraged to liaise extensively with care staff and families from the PMLD community, drawing on their expertise and knowledge to develop evidence-led policy. If commissioning research with participatory arts practitioners, policy makers should necessitate familiarity with the NHS ethics approval process. This is a complex undertaking with a number of potential stumbling blocks to progress and approval, particularly where activities that are deemed high risk are included. However, it can enable researchers to develop an ‘assurance passport’ to reassure gatekeepers and key supporters.

Policy approaches that build on the provision of arts-based activities in day services or other adequate locations can be used to develop the social and cultural lives of people. Where participatory artists are recruited into services, funding must be given to the provision of arts materials of the appropriate quality and for training of care staff in their use in order to give people with PMLD the best possible creative experiences. The conditions and principles for ME developed in this study could be tested with service providers and organisations that are interested in developing their leisure or creative offer to people with PMLD. There are rich potentialities to develop understandings of the usefulness of these models, and to advance them. Investigations could be made about the ways in which the conditions and principles develop opportunities to widen the interactions of those attending day services with people from the broader community. Creative-
enablers and those undertaking participatory action and practice-led research are ideally positioned to utilise the methods discussed in the individual case studies in order to support the development of this underrepresented population. Beyond the setting accessed for this doctoral study, the learning co-developed with its 7 participants can be a model for other practitioner-researchers working with other learning disabled and PMLD groups. Those working with collaborative arts approaches could undertake comparative studies that investigated artful processes and outcomes both participant-led and developed between learning disabled and non-learning disabled artists. My two peer reviewed publications (Appendices E and F) demonstrate the transferability of the models of practice framed in this study, providing both a research design and methodological framework for such future work.

As the 7 participants involved in this study led us into the evolution of their creative processes, relational dialogues were developed with materials, other participants and ourselves from their perspectives. Learning then was emergent and co-developed, and traditional research hierarchies redistributed. Reflexive research practices were critical though in ensuring that the lure of celebratory narratives did not obfuscate the ‘messy’ realities of attempting to conduct research inclusively in a practice-led setting. In the face of such challenges, this study has shown that the ME it identified established an expressive dimension in the lived experiences of its participants.
Works Cited


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---. *The Device Laid Bare: On Some Limitations in Current Art Criticism. E-flux journal*


Stalker, Kirsten. “Some Ethical and Methodological Issues in Research with People with


28 March 2014

Melaneia Warwick
PhD Candidate (AHRC)
CRD, University of Brighton
Grand Parade
Brighton
BN2 0JY

Dear Melaneia

Study title: How can adults with profound and multiple learning disabilities (PMLD) participating in inclusive arts workshops inform an understanding of meaningful engagement in this context?

REC reference: 14/LO/0264
IRAS project ID: 147350

Thank you for your letter of 24 March 2014, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Assistant Hayley Fraser, NRESCommittee.London-QueenSqaure@nhs.net

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the Committee has approved this research project for the purposes of the Mental Capacity Act 2005. The Committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.
Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.
Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee’s best wishes for the success of this project.

Yours sincerely

Dr Gella Richards
Chair

Email: NRESCommittee.London-QueenSqaure@nhs.net

Enclosures: List of names and professions of members who were present at the meeting.

"After ethical review – guidance for researchers" [SL-AR2]

Copy to: Professor A Tomlinson, University of Brighton
NRES Committee London - Queen Square

Attendance at Sub-Committee of the REC meeting on 29 March 2014

Committee Members:

<table>
<thead>
<tr>
<th>Name</th>
<th>Profession</th>
<th>Present</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Simon Eaton</td>
<td>Senior Lecturer in Paediatric Surgery and Metabolic Biochemistry</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Ms Katie Harron</td>
<td>Statistician</td>
<td>Yes</td>
<td></td>
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<tr>
<td>Dr Gella Richards</td>
<td>Psychologist</td>
<td>Yes</td>
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Also in attendance:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position (or reason for attending)</th>
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</thead>
<tbody>
<tr>
<td>Ms Hayley Fraser</td>
<td>Assistant Co-ordinator</td>
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</tbody>
</table>
Appendix B  IRAS Application
**Welcome to the Integrated Research Application System**

**IRAS Project Filter**

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

**Please enter a short title for this project** (maximum 70 characters)
Inclusive Arts & the Meaningful Engagement Agenda for Adults with PMLD

**1. Is your project research?**
- Yes
- No

**2. Select one category from the list below:**
- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

**If your work does not fit any of these categories, select the option below:**
- Other study

**2a. Please answer the following question(s):**

a) Does the study involve the use of any ionising radiation?
- Yes
- No

b) Will you be taking new human tissue samples (or other human biological samples)?
- Yes
- No

c) Will you be using existing human tissue samples (or other human biological samples)?
- Yes
- No

**3. In which countries of the UK will the research sites be located?** *(Tick all that apply)*
- [ ] England
- [ ] Scotland
- [ ] Wales
- [ ] Northern Ireland

**3a. In which country of the UK will the lead NHS R&D office be located:**
4. Which review bodies are you applying to?

- NHS/HSC Research and Development offices
- Social Care Research Ethics Committee
- Research Ethics Committee
- National Information Governance Board for Health and Social Care (NIGB)
- National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- Yes
- No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

- Yes
- No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

- Yes
- No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

- Yes
- No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- Yes
- No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?
9. Is the study or any part of it being undertaken as an educational project?

- Yes  - No

Please describe briefly the involvement of the student(s):
The PhD candidate is making this application as the Chief Investigator of the project. There are three academic Supervisors for this project who are from the Universities of Brighton and South Wales.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

- Yes  - No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

- Yes  - No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

- Yes  - No
**PART A: Core study information**

### 1. ADMINISTRATIVE DETAILS

#### A1. Full title of the research:

How can adults with PMLD accessing an inclusive arts intervention inform the development of the meaningful engagement agenda?

### A2-1. Educational projects

#### Name and contact details of student(s):

**Student 1**

<table>
<thead>
<tr>
<th>Title</th>
<th>Forename/Initials</th>
<th>Surname</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Melaneia</td>
<td>Warwick</td>
</tr>
</tbody>
</table>

**Address**

27 Everswell Road
Cardiff
CF5 3DH
melineiawarwick@googlemail.com
07540377941

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

**PhD**

Name of educational establishment:

University of Brighton

#### Name and contact details of academic supervisor(s):

**Academic supervisor 1**

<table>
<thead>
<tr>
<th>Title</th>
<th>Forename/Initials</th>
<th>Surname</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Professor Alan</td>
<td>Tomlinson</td>
</tr>
</tbody>
</table>

**Address**

CRD, University of Brighton
A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- Student
- Academic supervisor
- Other

A3-1. Chief Investigator:
A. Tomlinson@brighton.ac.uk
Brighton
May 2014 & June 2015

Welcome to the Integrated Research Application System
IRAS Project Filter
The integrated dataset required for your project...

It is unlikely that there will be fluctuation in the capacity of participants to consent as the condition is not one that...

Context Matters: Artist Residencies

Observations of the participants...

Registration of research studies is encouraged wherever possible. You may be able to register your study through
A5-2. Is this application linked to a previous study or another current application?  
☐ Yes  ☐ No  

**Please give brief details and reference numbers.**

---

### 2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

---

#### A6-1. Summary of the study.  
*Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

There has been a "broadening of attention" (Felce and Perry, 1995, p.1) to the lives of people with disabilities and this is aligned to a recent social policy shift in the perceptions about, and aspirations for people with PMLD (Mansell, 2010). The Mansell Report created a focus of interest in the barriers profoundly disabled people face and added further recommendations to policy makers about the importance of meaningful day activities.

Valuing People (DoH, 2001) was the first policy to focus on the needs of people with Learning Disabilities in 30 years. Despite its attempts to meet the citizenship, social rights and full participation needs of people with learning disabilities, the policy met with criticism from both advocates of people with profound and multiple learning difficulties and from the learning disabled community. A follow up policy Valuing People Now was later developed (DoH, 2009).

Although recent policy supports the meaningful engagement of people with PMLD, the role that the arts can play in this is not well understood. This research is informed by a practice-led project where the researcher will be creating an inclusive arts intervention with people with PMLD and their carers.

Two short films will be produced as outcomes of the project case studies. Whilst celebrating the achievements of the participants with PMLD, these will also serve to share the processes developed, the challenges that were overcome, and skills that were acquired during the intervention. This is the learning that will inform the meaningful engagement agenda. A series of best practice recommendations will be made to inclusive arts and health care practitioners, carers, family members, academics and policy makers.

---

#### A6-2. Summary of main issues.  
*Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

The main Project Management issues are:

- Recruiting both carer participants and participants with PMLDs. This process is described in full in Sections A27 – 35 can be seen in the Flow Chart in Appendix X.
- Managing a number of project participants. The Chief Investigator will use her project management skills and experience to ensure an efficient and organised approach to the project is maintained. The Chief Investigator will have the on-going support of her co-supervisors and of the NHS Trust.

The main project risks are:

- This research project has been designed in order to minimise risk to participants by ensuring that there is a robust
approach to obtaining consent and recruiting, in addition it will be clearly communicated to participants that they can leave the research at any time. A thorough consultation process has taken place in order to ensure that the research project has been ethically designed. Experience has shown that benefits can be said to outweigh risks as previously arts activities carried out with people who have PMLD have proved to be stimulating and enjoyable.

* A professional development training workshop will be attended by Carers participating on the project in order to increase their understanding of the content and purpose of inclusive art making activities, as well as of their role in the process. This will facilitate the reduction in risk of carers not understanding or valuing the importance of their role in the inclusive arts setting.

The main ethical issues of this research study are:

* Ensuring that participants are not coerced into taking part in the research. The procedures for recruitment have been designed to minimise this risk and can be seen in Sections A27 – 35 and in the Recruitment Flow Chart Appendix X.
* Ensuring that the correct procedures are followed so that participants with PMLD are able to be assessed as to whether they can give consent to participate. If they do not have the capacity to consent, ensuring that procedures to identify a Consultee as outlined in the Mental Capacity Act 2005 are followed. If they do have capacity, ensuring that consent given is done so in a fully informed way.
* The Chief Investigator has previous relevant research experience with people who have PMLD, and gained NHS ethical approval for this previous research in 2012. She is experienced and able to judge whether the person has capacity to consent to participate, and she will work closely with the Senior Occupational Therapist at the NHS Trust, Portsmouth in making this judgement. The Chief Investigator has completed her Good Clinical Practice training in order to support her skills in working with people who have PMLD.
* Ensuring that Carer participants are fully aware of the role they will play in the research and that they are therefore able to give informed consent to participate. Thorough Information Sheets have been devised as well as clear Consent forms, after discussion of these there will be a 3 week opportunity for Carers to consider whether they would like to be involved in the research.

Further information can be seen in Section A22.

The main confidentiality issues are:

* The fact that inclusive art sessions will be documented via video and photographs. Filmed sessions and photographs contribute to the actual research data and have a powerful role to play in the positive portrayal of people with PMLDs. Further information on this can be see in Section A22 Information and Consent forms will reflect the use of film and photographs. See Appendicies X.
* Participants could feel unhappy by their portrayal in photos / film and this could have a negative impact. The Chief Investigator is an artist experienced in documenting people with PMLD. She will carry out this work from this position and with respect to the participants. Participants will be invited to the first screening of the film made about the research project and to view the photographs that will be used in the final exhibition. They will have the opportunity to express their views and have changes made.

The main Legal issues are:

* Compliance with the Mental Capacity Act 2005 specifically sections 30 - 33. Part B of this form outlines the ways in which this will be done.

### 3. PURPOSE AND DESIGN OF THE RESEARCH

**A7. Select the appropriate methodology description for this research. Please tick all that apply:**

- [ ] Case series/ case note review
- [ ] Case control
- [ ] Cohort observation
- [ ] Controlled trial without randomisation
- [ ] Cross-sectional study
- [ ] Database analysis
- [ ] Epidemiology
- [ ] Feasibility/ pilot study
- [ ] Laboratory study
Welcome to the Integrated Research Application System

The integrated dataset required for your project will be created from the answers you give to the following questions.

1. What type of research are you planning to undertake?

☐ Metanalysis
☐ Qualitative research
☐ Questionnaire, interview or observation study
☐ Randomised controlled trial
☐ Other (please specify)

A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

How can adults with profound and multiple learning disabilities (PMLD) accessing an inclusive arts intervention inform the development of the meaningful engagement agenda?

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

Aim(s) of the investigation:
1) This research aims to investigate the access of inclusive arts interventions by groups of adults with PMLD.
2) This research aims to investigate how this access leads to insights that can support the development of the meaningful engagement agenda.

Research Objectives:
1) To identify the ways in which adults with PMLD engage with an inclusive arts intervention.
2) To identify what is perceived to be meaningful about this engagement.
3) To explore the ways in which carers support meaningful engagement in the inclusive arts setting.
4) To contribute to the understanding of the specific processes that are commonly utilised in order to facilitate inclusive arts interventions with people with PMLD.
5) To devise 2 films and a touring exhibition that present new ways of working meaningfully with adults with PMLD.
6) To contribute to the development of the meaningful engagement agenda through the dissemination of a series of recommendations highlighting best practices.

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

Mencap's PMLD Network has described people with profound and multiple learning disabilities (PMLD) as having "more than one disability, the most significant of which is a profound learning disability...and additional sensory or physical disabilities, health and mental difficulties and difficulty in communicating" (2013, p.3). It goes on to highlight the high level of support people will need in most of their daily lives and stresses that this support should be "person-centred, flexible and creative" (2013, p.7). There has been a "broadening of attention" (Felce and Perry, 1995, p.1) to the lives of people with disabilities and this is aligned to a recent social policy shift in the perceptions about, and aspirations for people with PMLD (Mansell, 2010). The PMLD Network states that the diverse needs of people with PMLD need to be met in "imaginative ways" (2001, p.12). Hope (2011, p.10) argues for an open-minded version of cultural expression that is person and community-centred and deifies the prescribed "expected forms of participation and communication of culture". Rather than the "often unresponsive environments" (Nind, 2008, p.1) people experience, there is room for the development of new inclusive, creative interventions that support choice-making and the expression of preferences.

The report Raising our Sights (2010) seeks to identify the barriers to people with PMLD going forward and is clear that the "major obstacles to wider implementation of policy...are prejudice, discrimination and low expectations" (Mansell, 2010, p.2). In addition there is an emphasis on the importance of meaningful engagement with activities in order that people can obtain a good quality of life "outside the home...(and) in the community" (Mansell, 2010, p.28). The term meaningful engagement first appears in Mansell's 2010 review of services for adults with PMLD where it is used in the form of a recommendation to local authorities about the ways in which adults could engage in "employment and day activity" (p.14). Mansell states that local authorities should "ensure that adults with profound and multiple learning disabilities are able to take part in a wide range of meaningful activities – including employment, education and leisure activities" (DoH, 2011, p.14). The term is subsequently utilised by the Department of Health in their response to the Mansell Report where it is linked with Government’s aspiration to “support people to have fulfilling lives including opportunities to...enjoy social and leisure activities” (DoH, 2011 p.14). In this policy context then, ‘meaningful engagement’ remains a problematic term that lacks clear definition and is not linked to any concrete philosophical position. It is however, aligned to notions of ‘fulfilling lives’ and social and leisure activities.

Despite these challenges, it will be possible to operationalise the term for this project within a quality of life framework that integrates two variables: choice making and expression of preference (Felce and Perry, 1995; Gray and Malins,
2004; Kearney and McKnight, 1997. Although a range of factors have been described in attempts to define quality of life (Felce and Perry, 1995) preference and choice appear most frequently in the literature (Kearney and McKnight, 1997). A number of reasons have been given for the frequency of these terms, and two are particularly pertinent to this study, firstly expression of preference and the ability and opportunity to make choices have a direct impact on the services people can access and receive. As Cannella et al. have stated:

Of great importance is the potential for choice interventions and preference assessments to lead to changes in the overall protocol for providing services to individuals with severe to profound developmental disabilities

(2004, p.9)

Secondly, there is a clear opportunity “to flexibly define preference and choice narrowly or broadly as necessary” (Kearney and McKnight, 1997, p.219) and this is key where participants have unique communication styles and understanding of these involves a number of parties. It is clear that people with PMLD do express preferences and can make a good number of choices within the context of their daily life. As this project will be investigating the nature and quality of these communications, care teams will advise the researcher on the assent and consent positions of participants and a baseline will be established to ascertain what these look like. In addition the study will ascertain which preferences they currently express that might be important to the study, for example those related to creative activities, so that they become “in charge of decisions about their artistic creations” (Lacey and Ouvry, 1990, p.210).

Arts-based projects have the potential to transform lives and communities (Belfiore and Bennett, 2008, p.3) and to support people with PMLD to express themselves and to make choices (Mencap, 2009). This project positions expression of preference and choice making as indicators for quality of life, it proposes the arts as a tool for exploring and informing these concepts by linking them to the meaningful engagement agenda and it aims to build on the small body of practice-led literature that connects the engagement of people with PMLD to the arts (Touch Trust, 2013; Project Artworks, 2012). In order to support people to access the inclusive arts intervention, accompanying care staff will receive training in the principles and processes of working inclusively in an arts-setting, enabling them to develop their skills in the area and to notice “how people react to someone who has different expectations of them” (Lacey and Ouvry, 1990, p.211).

Research supports the potential of film as a tool for giving voice and increasing the visibility of people with learning disabilities (Rojas and Sanahuja, 2011) and in enabling them to express, and others to gain insights into what their views might be (Ware, 2004). In social research practices, Boxall and Ralph stress the potential of this tool to enable a wider audience to consider the “point-of-view of people who continue to be underrepresented in intellectual disability research” (2009, p.48). In this project, film has a dual role to play: it is both a tool for collecting and analysing the visual data collected in the workshops, supporting the emerging and ongoing understanding of a person’s preferences and choices. In addition it is a tool for participants and the researcher to engage in collaborative making, and an artefact representing the processes employed in this making. Used in this way film will create an innovative tool for understanding and sharing the meaningful engagement through the choices and preferences of people with PMLD. In its form as an artefact, film will be used to stimulate responses and generate material from stakeholders. In brief, film will be utilised as a mechanism for gathering evidence and creating a collaborative artistic product to in order to measure any alteration in the perceptions of others.

Identifying the gap in research:

Although recent policy supports the meaningful engagement of people with PMLD, the role that the arts can play in this is not well understood. An investigation to establish a definition of meaningful engagement and processes for implementing arts based interventions that can contribute to the development of social policy needs to be undertaken.

There is a clear gap in the literature of inclusive arts based projects with people PMLD attempting to gain NHS ethical approval. Although self-publishing their practice (Project Artworks, 2012), on the ground projects may not have a relationship with the academy. This means that very little learning exists in the form of academic research and this presents barriers to dissemination of practice in the wider practitioner community. There is a clear gap in the literature around tackling ethical approval processes and the methods by which inclusive arts research can be articulated within the NHS structure (NRES NHS, 2012), a clear opportunity still exists to feedback research findings to ethical approval bodies (Iacono, 2012).

There is a very small literature based in practice that is beginning to concern itself with meaningful activities in respect to the form these might take. However this is limited and there are gaps in what the impact of these to policy beyond local lessons might be. This research will develop local outcomes into best practice processes and approaches with the aim of impacting on a broad audience nationally, and to affect a better understanding of how we might work more effectively with people with PMLD.

The research project aims to:
1) This research aims to investigate the access of inclusive arts interventions by groups of adults with PMLD.

2) This research aims to investigate how this access leads to insights that can support the development of the meaningful engagement agenda.

The project will analyse data in the following ways:

- By identifying patterns and other trends linked to the subjective choices made by the project participants during and across project workshops.
- By processing ongoing observations from carer reflections gained post and across the inclusive arts workshops.
- Through the identification of observations and emerging themes gained from stakeholders attending the art exhibition phase of the project.

More information can be seen in Section A62

References


A13. Please summarise your design and methodology. It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.

Methodology is based in the qualitative tradition, rooted in a pragmatic epistemology. It informed by an innovative mixture of inclusive arts practice and inclusive, action research and participatory traditions that support the project's practice-led focus and enables the researcher to make use of her tacit knowledge in the field. Action-research is built around the commitment to include its participants as collaborative partners in its research processes so that they become fully conversant with them. It is aligned to arts-based and inclusive research practices in its change-making concerns and although not always focused on the flattening of power structures in research relationships, it does look to those in higher positions to buy into its proposed actions (Wisker, 2008; Schostak and Schostak, 2008). This research methodology involves the consideration of a broad range of literature and fits well with the range of policy, theory, legal and arts-based documents that inform the practice and theory building of practitioners working in the areas of learning difficulties and profound and multiple learning disabilities. It is based on ongoing action and reflection cycles and is often interpretive and constructivist in its approach (Wisker, 2008) and involves a spiral or cycle of planning, action, monitoring and reflection.

The design of the study is informed by McNiff's model of action-research as spirals on spirals (1988) which convey the characteristics of this type of inquiry, these iterative cycles will enable insights to be fed back in and tested as they emerge. This study will utilise case-study by design and inclusive arts practice methods to gain an understanding of context specific knowledge.

This research is informed by a practice-led project where the researcher will be creating an inclusive arts intervention with people with PMLD and their carers. Inclusive arts practice can be defined as “supporting creative opportunities between marginalised and non-marginalised people through artistic facilitation and collaboration as a means of challenging existing barriers and promoting social change” (Fox, 2008). To date there is little academic research accompanying this widespread practice but there have been a number of notable projects in the last decade (Smudged at the Tate Modern, a2a; Transitions, Project Artworks, 2012; Touching Lives, Touch Trust 2009). This inclusive arts intervention will provide a site for academic investigation.

This research has been designed on ethical principles of respect for persons, beneficence and justice as outlined in the Belmont Report (Macfarlane, 2009). Once in progress, the action-research model will make use of the tacit, intuitive knowledge (Gray and Malins, 2004) that the Chief Investigator has in delivering inclusive arts workshops to people with PMLD. The Chief Investigator will make the assumption that a self-evaluative involvement in the research...
The research will be conducted around the following practical framework:

Oct 2013 – April 2014

Contextual Review
Literature Review

The Chief Investigator will look at a range of materials including published literature and 'live' contextual information such as visual examples from practice-led arts workshops with people who have PMLD. This part of the research equates to the 'plan' step in the action-research cycle (McNiff, 2002).

Identifying potential participants - April 2014 & May 2015

The Chief Investigator will identify all potential participants who meet the inclusion criteria.

For potential participants with PMLD a postal invitation will be sent out inviting key people that prospective participants may want to be consulted to meet and discuss the project further. The Chief Investigator will then meet with key people, explain the project further and explain that a capacity assessment will need to be conducted.

For potential carer participants a postal invitation will be sent out them to meet and discuss the project further.

This part of the research equates to the 'plan' step in the action-research cycle (Waters-Adams, 2006; McNiff, 2002).

Assessing Capacity to Consent  April 2014 & May 2015

The research assistant will conduct meetings with potential research participants who have PMLD in order to ascertain whether they have the capacity to consent. Potential participants will be joined by key people in these meetings.

This part of the research equates to the 'plan' step in the action-research cycle (Waters-Adams, 2006; McNiff, 2002).

Gaining Consent  April & May 2014; May & June 2015

If the potential participant with PMLD does have the capacity to consent, the project will be explained to them and the Consent forms looked at.

If the potential participant does not have the capacity to consent, the Chief Investigator will identify Consultees for each person. Consultees will be invited to a meeting where the project can be discussed and the consultee invited to make a best interest decision about the person joining the project. This may be a group meeting, one-to-one meetings or telephone meetings.

The Chief Investigator will invite prospective carer participants to meet and discuss the research project. This may be a group meeting, one-to-one meetings or telephone meetings. She will explain what the project entails and go through the Consent and Information sheets. All carers will have the capacity to consent.

The meetings and discussion are planned to take place in the first two weeks of November. There will be a two week period allocated where all potential participants and Consultees and can consider their decision / best interest decisions.

This part of the research equates to the 'plan' step in the action-research cycle (Waters-Adams, 2006; McNiff, 2002).

A flow chart outlining the recruitment process for this project can be seen in Appendix X

Carer Participant professional development workshop  May 2014 & June 2015

Carers undertake a one-day professional development workshop and sharing of information that will best support people in the project. Guided reflection on:

- The role of the carer in the inclusive arts setting
• How the carer can support their client in the inclusive arts setting
  • Ownership of artworks
      * Current preferences, if any, a person has in relation to creative activities

Examples of reflective questions carer participants may be asked include:

* What have you learned about the roles of artmaker and helper?
* How might you support a person with PMLD to make choices in the Inclusive Arts Setting?
* How might you support a person with PMLD to express a preference in the Inclusive Arts Setting?
* How might you support a person with PMLD to create artworks using their own skills and abilities?

This part of the research equates to the ‘act’ and ‘observe’ steps in the action-research cycle (Waters-Adams, 2006; McNiff, 2002).

A detailed description of this workshop can be found in Appendix X.

Inclusive Arts Interventions May - September 2014; May - September 2015

Two 20 week inclusive arts interventions will be facilitated and recorded using film and photographs which will form part of the data collected for the research project. These sessions will include a range of arts-based activities which focus on the promotion of choice-making through, for example, material and scale. Individual participant’s choices will be recorded.

Participants or their consultees will have given consent for identification to be possible in the recorded data and for it to be used in the following settings:

* Brighton University towards PhD thesis
* Conferences with a focus on disability / the arts
* Touring exhibition with a focus on the artwork made by research participants
* Talks, conference papers and journal articles
* Professional development workshops for Carers and Support Workers

This part of the research equates to the ‘act’ and ‘observe’ steps in the action-research cycle (Waters-Adams, 2006; McNiff, 2002).

Film and photographs will be taken by the Chief Investigator who is an experienced artist and has worked with people with PMLD in the UK for over 5 years. More on the use of film and photography can be found in Section A22.

There will be 1 session a week for 3 hours. A detailed description of these activities can be found in Appendix X.

Collaborative Editing of the Films April 2016

Carers, participants with PMLD, key people and Consultees will be invited to a screening of the film made as part of the research project. They will be invited to collaborate on changes to the film. Changes can be made to the film will be made post this screening.

This equates to the ‘reflect’ step in the action-research cycle (Waters-Adams, 2006; McNiff, 2002).

Validity

A Steering Group has been formed in order to review the study design against the project aims and timeline. This people involved in this Group are:

University Members

David Haines
Research Project Co-supervisor
Senior Lecturer
University of Brighton
Tel: 01273 643953
External Advisory Members:

The design, undertaking and dissemination of the project has gained from the feedback of this experienced group and has focused on:

The research project has also been looked at and approved by the University of Brighton’s Faculty Research and Ethics Governance Committee.


A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- Design of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings

Give details of involvement, or if none please justify the absence of involvement.

A group of carers have been invited to evaluate the Information and Consent Sheets for carers as part of the design process of the research project.

Project participants will be invited to collaborate on the content of the films created, both in the making and editing of them, thereby affecting the way in which the research findings are disseminated.

Adults with PMLD will be undertaking participation in research that is about them.

Through their choice-making participants with PMLD will affect the design of the research as part of the action-learning cycle.

Carers will be involved in the analysis of the research results through the observation of film data. Their involvement will support the triangulation of results.

4. RISKS AND ETHICAL ISSUES
### RESEARCH PARTICIPANTS

**A17.1. Please list the principal inclusion criteria (list the most important, max 5000 characters).**

Inclusion Criteria for People with Profound and Multiple Learning Disabilities:

1. People who fit the definition of having Profound and Multiple Learning Disabilities as outlined by the PMLD Network.
2. Adults with PMLD who attend the NHS Trust, St James’ Hospital, Portsmouth.
3. People who have either given informed consent to participate, or for whom a best interest decision has been made by a consultee as described by the Mental Capacity Act 2005.

Inclusion Criteria for Carer Participants:

Carers play an important role in the sharing of stimuli with people they regularly work with (Vlaskamp, 1999) and their role in supporting participants in their art-making cannot be underestimated. Consequently it is the case that carers who are paid and/or family members and will become participants in the research project.

1. Have the capacity to consent to participate in the research.
2. Regularly care for one of the project participants with PMLD either in a professional, paid role or as a family member.
3. Have attended the professional development workshop for carers.

**A17.2. Please list the principal exclusion criteria (list the most important, max 5000 characters).**

Exclusion Criteria for People with Profound and Multiple Learning Disabilities:

1. People with PMLD who not have either given informed consent to participate, or for whom a best interest decision has not been made by a consultee as outlined by the Mental Capacity Act 2005.
2. People whose behaviour cannot be managed and therefore will present a threat to any other vulnerable people in the room.
3. People who are too tired or unwell to participate.

Exclusion Criteria for other people:

1. People who are not participating in the research project.
2. Do not regularly care for one of the project participants with PMLD.

### RESEARCH PROCEDURES, RISKS AND BENEFITS

**A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.**

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.
Part A: Core study information

Welcome to the Integrated Research Application System (IRAS) Project Filter. The integrated dataset required for your project must be submitted with the application. It is unlikely that there will be fluctuation in the capacity of participants to consent as the condition is not one that would fluctuate. Please ensure that all information is accurate and up to date.

1. Intervention or procedure

<table>
<thead>
<tr>
<th>Intervention or procedure</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ascertaining the ability of potential participants with PMLD to consent to participate</td>
<td>1</td>
<td>0</td>
<td>30 mins</td>
<td>The Chief Investigator will work with each participant with PMLD and key people they might like to have with them using best practice guidelines as laid out in Section 32(3) of the Mental Capacity Act 2005. This will be carried out at the NHS Trust site.</td>
</tr>
<tr>
<td>Seeking consent for person with PMLD who cannot consent to participate</td>
<td>1</td>
<td>0</td>
<td>1 hour</td>
<td>The Chief Investigator will work with each individual participant with PMLD or the Consultant using best practice guidelines as paid out in Section 32(3) of the Mental Capacity Act 2005. This will be carried out at the NHS Trust site.</td>
</tr>
<tr>
<td>Documenting of each inclusive arts session using film and photography</td>
<td>20</td>
<td>0</td>
<td>3 hours</td>
<td>This will be carried out by the Chief Investigator within sessions attended by participants at NHS Trust Day Care services. Participants will also be invited to film their experiences themselves.</td>
</tr>
<tr>
<td>Analysis of film data with participant carers at regular interval during the project</td>
<td>6</td>
<td>0</td>
<td>2 hours</td>
<td>This will be carried out by the Chief Investigator at the NHS Trust site.</td>
</tr>
<tr>
<td>Observations of the participants with PMLD and their participant carers within the inclusive arts interventions</td>
<td>20</td>
<td>0</td>
<td>3 hours</td>
<td>This will be carried out by the Chief Investigator at the NHS Trust site.</td>
</tr>
<tr>
<td>Informal evaluation and discussion with participants at the end of each inclusive arts workshop</td>
<td>20</td>
<td>0</td>
<td>30 minutes</td>
<td>This will be carried out by the Chief Investigator at the NHS Trust site.</td>
</tr>
</tbody>
</table>

A21. How long do you expect each participant to be in the study in total?

Participants will be involved in the study over a 20 week period. This will run from May 2014. During this period each Carer participant would undertake a one day professional development workshop; all participants would be involved in 60 hours of Inclusive Arts workshops with each workshop lasting for 3 hours.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

This research project has been designed in order to minimise risk to participants by ensuring that excellence in ascertaining their ability to consent, obtaining consent and therefore recruiting exits (A Flow Chart outlining the recruitment process for participants with PMLD can be seen in Appendix X). In addition Carers have been consulted on the design of the project. The project aims to ensure that communication to participants clearly emphasises, and regularly reiterates that they are able to leave the research at any time.

Risks, Burdens and Benefits

1) People with PMLD belong to an under researched group

People with PMLD form a “small but ignored minority” (Carnaby, 2004 p.6) in society. There are clear indicators of, and recommendations to policy makers about the barriers people face in obtaining a good quality of life and the importance of ‘meaningful engagement’ in “day activities outside the home... (and) in the community” (Mansell, 2010, p.28). Although recent policy supports the meaningful engagement of people with PMLD (DoH, 2009), the role that the arts can play in this is not well understood. An investigation to establish a definition of meaningful engagement and processes for implementing arts based interventions that can contribute to the development of social policy needs to be undertaken.

There is a very small literature based in practice that is beginning to concern itself with meaningful activities in respect to the form these might take. However this is limited and there are gaps in what the impact of these to policy beyond local lessons might be. This research will develop local outcomes into best practice processes and approaches with...
the aim of impacting on a broad audience nationally, and to affect a better understanding of how we might work more effectively with people with PMLD.

Choice-making is a key aspect of Valuing People (Department of Health, 2001) and its exploration in research is highly valuable (Carnaby, 2004). However there is limited support in terms of literature or otherwise to enable carers to understand approaches that could support people with PMLD to make meaningful choices (Carnaby, 2004).

The design of the research project has been made in consultation with Carers whose feedback and thoughts are reflected. Conclusions reached from the running of the research project will be shared with academics, Inclusive Arts practitioners, Carers and other key stakeholders. This will happen in academic contexts such as conferences and in professional development settings, such as workshops for Carers, with the aim of adding to thinking and practice around how people with PMLD might be best supported.

With the careful consultation in the design of the project adding to its final form, it is anticipated that benefits can be said to outweigh risks for those participating in it. More can be see on Consultation in Section A14-1.

2) Risk of individuals not remaining anonymous and their portrayal being perceived as negative

“The Arts are an expression of who we are” (Mencap, 2008) and individual expressions are valued greatly in the Inclusive Arts setting. However, it is essential that individuals participating in the research project are happy about how their images are shown to a wider audience. Mencap’s (2008) guidebook on consent for videos and photographs of people with PMLD has been closely referred to in the development of Consent and Information sheets (Appendices X). It will act as guide throughout the project lifecycle.

The portrayal of people with PMLD can help to raise awareness of their lives. It is also a powerful vehicle for enabling their individual voice to be heard (Mencap, 2008), visual material that shows participants in the art-making process gives them a vehicle for representing themselves in a way that may not be achieved through language. This is also true when people with PMLD are empowered to film their own experiences if they wish. In order for inclusion to happen in the research process ways need to be employed for documenting what people think about interactions they are having and what is happening around them. “Some of the more conventional strategies are of no use for compiling, illustrating or disseminating the visions or points of view of some groups...” (Rojas and Ma Sanahuja, 2011, p33) A key aim of this research project is to share the achievements of people with PMLD in a public setting thereby enabling a variety of people to see them. The nature and complexity of visual information means that there is an increased opportunity for people with PMLD to be heard.

All participants will receive a copy of the film used in the final exhibition.

Ensuring that informed consent is gained and that participants or their Consultees are fully aware about where the images will be shown are key parts of the research project. Part of this will be to state clearly that there will be opportunities for participants with PMLD, their carers, families and Consultees to participate in the editing of the films, in order to ensure that the images to be used in exhibitions or elsewhere are acceptable. Regular showings of photographs will be made available as the project progresses so that participants and key people can state whether they are happy for them to be used. Mencap clearly states that participants will have the final say in whether images of them are to be used (2004) and this will be adhered to.

3) Risk of consent not being fully informed

All consent gained will be done so via a model that allows participants multiple and ongoing options to choose not to remain in the project (Recruitment Flow Chart – Appendix X).

All Consent and Information forms have been designed and developed, in some cases collaboratively, to meet the needs of a number of potential participants and their Consultees. These forms provide participants with clear information on the research project, are direct, and make use of uncomplicated language, images and symbols where appropriate (see Forms in Appendixes X). This is to minimise the risk of information about the project not being understood by anyone who will have an involvement with it.

In order to allow potential participants or Consultees good time to consider all aspects of the project and to ask questions, there is a 2 week period in which they can respond and indicate how they wish to proceed.

Once consent has been gained, Consultees will be regularly informed of the progress of the project and encouraged to visit it. More about this can be found in Sections A27 and Section B.
4) Risk of Confidentiality and Anonymity not being maintained

Please see Section A38


A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

☐ Yes  ☐ No

*If Yes, please give details of procedures in place to deal with these issues:*

The project has been carefully designed to minimise any discomfort on the part of participants. It has been looked at by its Steering Group and approved by the University of Brighton Faculty Research Ethics and Governance Committee (Appendix X).

It is possible during the reflection phase of the professional development workshop participant carers may reveal that they felt discomfort or other difficult emotions whilst undertaking the art making. It is possible that some Carers would find emotive any observation and discussion of the film data collected.

The purpose of the Inclusive Arts development workshop is to further enable Carers to support participants with PMLD to be as independent as possible in their art-making activities (further discussion of this can be found in section A13). The purpose of the involvement of the Carers in the observation of film data is to support the person with PMLD to be heard through the careful triangulation of research conclusions. This is clearly explained on the Information Sheets for Carer participants and for participants with PMLD and their Consultees.

In the case of discomfort or other difficult emotions being expressed by Carer participants the Chief Investigator will ensure that:

1) The Carer participant is reminded of the focus of the questions being asked. For example:

- What have you learned about the roles of art-maker and helper?
- How might you support a person with PMLD to make choices in the Inclusive Arts setting?
- What can we see in this piece of film that will help us to understand that a person is making a choice or expressing a preference?

2) The Carer participant is signposted to his / her team to discuss any issues that have arisen.

3) The Carer participant is reminded that they can withdraw from the study at any time.

It is also possible that participants with PMLD could become distressed when discussions are going on at the start and end of Inclusive Arts workshops. A goodbye routine will be established where looking at artwork, individual praise for participants and reflective discussion with Carers happens. Also included will be the chance to share and show with peers. The Chief Investigator will record key pieces of feedback from this part of the session. The reflective discussion combined with observations from session will inform the collaborative design of the project as part of the on going action-research cycle. The Chief Investigator will ensure that she has gained familiarity with how participants with PMLD express frustration or distress and would work with Carers to ensure that:

1) Any participant who was showing signs of frustration or distress would be shown a quiet space where they could be comforted and calmed until they were ready to rejoin the group, or to leave for home.

2) Key people and Consultees would be reminded that participants could withdraw from the research and would be supported to do so at any time.

A24. What is the potential for benefit to research participants?
1) This research will offer participants with PMLD an opportunity to gain from the stimulation, variation and challenges (Valskamp and Nakken, 1999) that working with visual arts provides.

2) Mencap has outlined 9 key reasons why people with PMLD should have opportunities to participate in the arts (Mencap, 2009). These include the opportunity to express themselves non-verbally and gain an increase in self-confidence and social skills.

3) Recent social policy shift in the perceptions about, and hopes for people with PMLD (Mansell, 2010) have meant a positive focus on how they can meaningfully engage with social and educational activities. The PMLD Network states that the diverse needs of people with PMLD need to be met in “imaginative ways” (2001, p.12) and participation in the arts may be able to provide this opportunity.

4) Choice making is important to people who have PMLD and in the Inclusive Arts setting and the onus is on Carers and the Arts Practitioner to effectively listen and respond to what people are communicating. This enables people with PMLD to experience control and to develop relationships. (The Foundation for People with Learning Disabilities, 2001)

Points 1 – 4 would be beneficial areas of development for people with PMLD without the capacity to consent.

4 ) This research aims to contribute to the academic rigour and best practice in the field of Inclusive Arts and thereby inform other arts practitioners who work alongside people with PMLD.

5) This research aims to contribute to the evidence base in the field by developing understanding around the role of the Carer in the Inclusive Arts setting.


**A26. What are the potential risks for the researchers themselves? (if any)**

Some people with PMLD can sometimes display challenging behaviour including physical aggression towards others. Each participant with PMLD will be accompanied by one or two carers who will know them very well and understand their behaviour. The Chief Investigator will have spent 6 weeks at the NHS Trust working closely with participants and their carers, prior to the start of the workshops in order to ensure that she is aware of any challenging behaviour that a participant may display and of any triggers for the behaviour.

The Chief Inspector has gained professional experience in delivering Inclusive Arts workshops for people with PMLD. In addition she has completed the Good Clinical Practice Training (See CV Appendix X).

**RECRUITMENT AND INFORMED CONSENT**

_In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate._

**A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of social care or GP records, or review of medical records. Indicate whether this will be done by the direct care team or by researchers acting under arrangements with the responsible care organisation(s).**

Participation onto the research project will be offered to attendees of the NHS Trust, St James’ Hospital, Portsmouth, specifically those attending Day Services and who are over 19 years old and have therefore passed the age where they can access statutory education services.

Attendees will already be accessing a range of Day Service activities as part of their attendance but none related to making art works. The Chief Investigator has experience of delivering arts workshops to adults of this age group.
Recruitment will happen using the following system:

- The Chief Investigator will be getting to know people attending day services for 6 weeks prior to the research project beginning. This will include working closely with their carers (paid or family members) to gain an understanding of their different ways of communicating preferences, and their assent and dissent positions.

- During this time she will inform people who are involved in key decisions about the life of the potential participants (these may be parents, siblings or other key people) about the research project and invited them to discuss the project. These might be group, one-to-one or telephone meetings.

- The Chief Investigator will ascertain whether a potential participant with PMLD has the capacity to consent to be involved in the project. She will ensure that where consent is given it is done so following the guidelines as laid out in the Mental Capacity Act (2005).

- If potential participants with PMLD do not have the capacity to consent, the Chief Investigator will look for a Consultee who can advise that it is in the interests of the person with PMLD participate in the research. She will be ensure that where consent is given it is done so by carefully following the guidelines in the Mental Capacity Act 2005.

- Carers (these may be paid carers or others such as parents) will be recruited onto the research project following a meeting where information is given both verbally and in writing.

- There will be a gap of 2 weeks for all participants to consider whether they would like to be involved in the research project.

- All potential participants will be reminded that they can withdraw from the study and be supported to do so at any time.

A Flow Chart describing the recruitment process can be seen in Appendix X.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

☐ Yes  ☐ No

*Please give details below:*

- Participants and their carers (either paid or others such as family members) will already be known to the Chief Investigator and she will have spent 6 weeks getting to know them prior to the start of the research project. The PMLD Network has described the quality of relationships in the lives of people with PMLD as a “critical factor” (PMLD Network, 2001); developing familiarity will have a positive effect on being able to support people in an Inclusive Arts setting.

- Written and verbal information will be made available to Carer participants when they attend a meeting to discuss the project (Participant Information Sheet 2).

- Written, pictorial and verbal information will be made available to participants with PMLD when they attend a meeting to discuss the project (Participant Information Sheet 3). During these meetings the Chief Investigator will assess the potential participant’s capacity to consent, she will talk about the project without making any assumptions around capacity to consent. If she ascertains that there is no capacity to consent then the Chief Investigator will ensure that Sections 30-33 of the Mental Capacity Act 2005 are followed and:

- Written and verbal information will be made available to people who will decide if it is in the best interests of the potential participant with PMLD to be involved in the project. These may be people that a potential participant would want to be involved in key decisions in about their life (Appendix X).

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

☐ Yes  ☐ No

A29. How and by whom will potential participants first be approached?

Carer participants

* The Chief Investigator will have been on site at the NHS Trust for 4 weeks prior to the research project beginning. She
will have spent this time working with Carers (family or paid carers) getting to know how individual group members communicate including how they express wishing / not wishing to participate. During this time (week 1) she will inform Carers about the research project verbally and invite them to contact her if they wish to learn more. This will minimise coercion by putting the carer in control of decision making.

Participants with PMLD

* The NHS Trust administrator will contact key people who prospective participants may want to be informed about the research project. They will be asked to contact the Chief Investigator if they are interested in learning more. This will minimise coercion by putting these key people in control of decision making.

* If key people are not available or do not wish to discuss the project the Chief Investigator will contact personal Consultees of prospective participants to inform them about the research project. They will be asked to contact the Chief Investigator if they are interested in learning more. This will minimise coercion by putting personal Consultees in control of decision making.

* There will be up to 2 weeks for participants or their personal Consultees to decide that they would like to participate in the research project and 2 weeks for consent to be obtained.

### A30-1. Will you obtain informed consent from or on behalf of research participants?

- **Yes**
- **No**

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

**Carer Participants**

The Chief Investigator will meet with potential participants and work through the participant information sheets and consent sheets (see Appendices X) in order to answer any questions. This may be done in small groups or a large group in order to ensure a lack of coercion.

**Participants with PMLD**

The process for gaining consent or a best interest decision for participants with PMLD is explained in Part B Section 6.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

### A30-2. Will you record informed consent (or advice from consultees) in writing?

- **Yes**
- **No**

### A31. How long will you allow potential participants to decide whether or not to take part?

The research project has been designed so that the maximum reflection and decision-making time is available for potential participants.

Carer participants will be able to give informed consent and will be asked to decide whether they would like to:

- Learn more about the research project - there will be a time frame of up to 2 weeks for this to happen.
- Participate in the research project - there will be a time frame of 2 weeks after being given the relevant written and verbal information.

If it has been ascertained that participants with PMLD are able to give informed consent will be asked to decide
whether they would like to:

• Learn more about the research project - there will be a time frame of up to 2 weeks for this to happen.
• Participate in the research project - there will be a time frame of 2 weeks after being given the relevant written and verbal information.

If it has been ascertained that participants with PMLD are unable to give informed consent their Consultees will be asked to decide whether they would like to:

• Learn more about the research project - there will be a time frame of up to 2 weeks for this to happen.
• Feel it is in the best interest decision for the person to participate in the research project - there will be a time frame of 2 weeks after being given the relevant written and verbal information.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters)

All Carers are employed to work in the UK and need to work closely with the families of people with PMLD. It is therefore assumed that they have a good understanding of English both in written form and verbally.

People with PMLD have a range of ways in which they communicate. Carers and parents have a very good level of understanding of this and the Chief Investigator can gain information from them. In addition the Chief Investigator will work with potential research participants for 8 weeks prior to beginning her research study. This will enable her to learn their communication strategies for how they feel including how they express unwillingness to engage in an activity.

Where people involved in the research cannot understand English provision will be made for interpretation. Additionally the Chief Investigator is an English as a Foreign Language (EFL) qualified tutor with over 10 years experience in working with people who are learning to communicate through English.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

☐ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

☐ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

☐ The participant would continue to be included in the study.

☐ Not applicable – informed consent will not be sought from any participants in this research.

☐ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:
Research data will be gathered via film. As it may be problematic to separate out parts of this documentation, it is likely that it would be retained for analysis.

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)
Access to medical records by those outside the direct healthcare team
Access to social care records by those outside the direct social care team
Electronic transfer by magnetic or optical media, email or computer networks
Sharing of personal data with other organisations
Export of personal data outside the EEA
Use of personal addresses, postcodes, faxes, emails or telephone numbers
Publication of direct quotations from respondents
Publication of data that might allow identification of individuals
Use of audio/visual recording devices
Storage of personal data on any of the following:
- Manual files (includes paper or film)
- NHS computers
- Social Care Service computers
- Home or other personal computers
- University computers
- Private company computers
- Laptop computers

Further details:
Film and photographic data will be collected as part of the research methodology for this project. It is possible that research participants could be identified from this documentation:

* All participants will be asked to give informed consent to the use of documentation. This is outlined in Appendices X.
* In the case of participants who are unable to consent, Consultees will be asked to make a decision in the person's best interest on the use of documentation. This is outlined in Appendix X.
* All documentation will be stored on a University computer under a secure password. See Section A38.
* All quotes will be anonymised once they have been gathered.

A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

There will be a number of measures taken to ensure confidentiality:

- Participants will not be referred to by name at any time. In the Chief Investigator will maintain a reflexive research journal throughout the study and employ a coding system that will not correlate to the initials of the participants' names.

- Names of all the research participants will be anonymised in the writing up of the research findings and in subsequent journal and conference papers and presentations.

- Direct quotes given by participant Carers will be used but names will be anonymised. The Information sheet refers to this and Carers are asked to consent to this via their Consent sheet (Appendices X).

- In the professional development workshop for Carers the Chief Investigator will ensure that all participants have the opportunity to withdraw any statements or feedback given.

- This research project aspires to share the achievements of people with PMLD in a public setting thereby enabling a variety of people to see their achievements and gain new understandings of how they might work with this group. Participants will be identifiable through video footage and photographs, however no footage will be shown on line. This will be referred to in the participant Information and Consent forms see Appendices X.

Further information around video and photographs can be seen in Section A22.
A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

No personal data about participants will be collected as part of this research study other than the documented inclusive arts sessions and collected of direct quotations which will be anonymised.

The data that is collected will be only accessible to the Chief Investigator. It will remain securely locked away in a cabinet if in physical form. As digital data it will remain on a University computer behind a password only known by the Chief Investigator.

In the write up of the research names of participants will be anonymised.

All of this information will be made available in the Participant Information Sheets (Appendices X) and either informed consent be obtained or consultee advice be sought as outlined in Section B6.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- Less than 3 months
- 3 – 6 months
- 6 – 12 months
- 12 months – 3 years
- Over 3 years

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

- Yes
- No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

- Yes
- No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

- Yes
- No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants’ General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

- Yes
- No
If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50-1. Will the research be registered on a public database?

☐ Yes  ☐ No

Please give details, or justify if not registering the research.
The Chief Investigator is not aware of a public database for the publication of this type of research at the present time. If though, one should be made available this research would be registered.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

☐ Peer reviewed scientific journals
☐ Internal report
☐ Conference presentation
☐ Publication on website
☐ Other publication
☐ Submission to regulatory authorities
☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
☐ No plans to report or disseminate the results
☐ Other (please specify)

* An overview of the research and its findings will be submitted to peer-reviewed journals for inclusion such as the British Journal of Learning Disabilities and the Journal of Intellectual Disability Research.
* Presentation of project methodology and findings within workshops for carers and other professionals working with people who have PMLD.
* Presentation of documented sessions using film and photographs and artworks to people with PMLD and other groups of people with LD.
* Presentation of project methodology and findings, visual documentation and a touring exhibition for PhD thesis.
* An overview of the research and its findings will be submitted for inclusion at conference such as the Embrace, Create, Connect Conference organised by the University of Leicester.

A53. Will you inform participants of the results?

☐ Yes  ☐ No

Please give details of how you will inform participants or justify if not doing so.

* A presentation of final film and photographs will be made to people with PMLD and other groups of people with LD.
* Presentation of inclusive arts methodology and findings within workshops for carers and other professionals working with people who have PMLD.
* Inclusive arts professionals and other interested stakeholders will be able to access the research via journals or by attending a conference.
* All participants will be invited to attend the touring exhibition.

5. Scientific and Statistical Review

A54-1. How has the scientific quality of the research been assessed? Tick as appropriate:
A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.

Total UK sample size: 42
Total international sample size (including UK):
Total in European Economic Area:

Further details:
This is the total maximum sample size. Each intervention will be approximately half of this total sample size (21 people).
Each participant with PMLD will be accompanied by up to 2 participant carers, all carers will participate in the study.

A60. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.

In each intervention there will be an intensive sampling as adopted in such fields as health care (Ky et al., 1988) that will narrow to the small, specific field of PMLD and that has between 5-7 participants.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

An action-based qualitative research methodology will form the overarching approach to the project.

The project will generate qualitative data in the forms of:

* Video footage of:
  - inclusive arts workshops for people with PMLD

* Photographic documentation of:
  - workshops for carers
  - inclusive arts workshops for people with PMLD

* Direct and written quotes from:
  - professional development workshop for participant carers
  - inclusive arts workshops for people with PMLD

* Artefacts from:
  - inclusive arts workshops for people with PMLD
* Chief Investigator's reflexive practice to include:
  - collage based artworks
  - written journal

Analysis

Analysis will be treated as a pervasive, reflexive process throughout the lifecycle of the project, as well as a way of understanding data once it has all been collected.

Huberman and Miles describe a triad of linked “subprocesses” (Coffey and Atkinson, 1996, p.7) (Gray and Malins, 2004) that act as key activities for data analysis. Their “data reduction, data display and conclusion drawing and verification” will provide a systematic approach in this research project, enabling a range of patterns and connections to occur, be described (as diagrams or other visual forms) and interpreted (Coffey and Atkinson, 1996, p.7) (Gray and Malins, 2004).

Data gathered through the Chief Investigator’s reflexive practice and the professional development workshop for carer participants, will be used to identify correlations, patterns and other connections to the Inclusive Arts Workshop data. These relationships will be presented in visual forms including diagrams, drawings and graphs, and through written analysis.

During the research project ongoing trends, themes and observations will be processed via the Chief Investigator’s reflexive journaling and issues and observations reported by Carers post Inclusive arts workshops. These observations will be clustered and displayed thematically and conclusions drawn in writing.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

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<tr>
<th>Title</th>
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<tr>
<td>Professor A</td>
<td>Tomlinson</td>
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<tr>
<td>Lead Supervisor</td>
<td>BA, PCGE, MA, D.Phil</td>
<td>University of Brighton</td>
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<td>Brighton</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Post Code</th>
<th>Telephone</th>
<th>Fax</th>
<th>Mobile</th>
<th>Work Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>BN2 0JY</td>
<td>+44 (0)1273 643223</td>
<td></td>
<td><a href="mailto:A.Tomlinson@brighton.ac.uk">A.Tomlinson@brighton.ac.uk</a></td>
<td></td>
</tr>
</tbody>
</table>

A64. Details of research sponsor(s)

A64-1. Sponsor

<table>
<thead>
<tr>
<th>Lead Sponsor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Status:</td>
</tr>
</tbody>
</table>
|              | NHS or HSC care organisation
|              | Academic
|              | Commercial status: Non-Commercial |
Contact person

Name of organisation University of Brighton
Given name Alan
Family name Tomlinson
Address Faculty of Arts, Design and Media, University of Brighton, Grand Parade
Town/city Brighton
Post code BN2 0JY
Country UNITED KINGDOM
Telephone +44 (0)1273 643223
Fax
E-mail A.Tomlinson@brighton.ac.uk

Is the sponsor based outside the UK?
☐ Yes  ☐ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?
☐ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☒ No application for external funding will be made

What type of research project is this?
☐ Standalone project
☐ Project that is part of a programme grant
☐ Project that is part of a Centre grant
☐ Project that is part of a fellowship/ personal award/ research training award
☒ Other

Other – please state:
Project that is part of a PhD

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?
☐ Yes  ☐ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.
A68-1. Give details of the lead NHS R&D contact for this research:

<table>
<thead>
<tr>
<th>Title</th>
<th>Forename/Initials</th>
<th>Surname</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Jo</td>
<td>Ball</td>
</tr>
</tbody>
</table>

Organisation: Solent NHS
Address: Solent NHS trust, Learning Disability Service, Kestrel Centre, St James Hospital, Locksway Road, Portsmouth
Post Code: PO4 8LD
Work Email: Jo.Ball@solent.nhs.uk

Details can be obtained from the NHS R&D Forum website: [http://www.rdforum.nhs.uk](http://www.rdforum.nhs.uk)

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/04/2014
Planned end date: 01/10/2015
Total duration:
Years: 1 Months: 6 Days: 1

A71-2. Where will the research take place? (Tick as appropriate)

- [x] England
- [ ] Scotland
- [ ] Wales
- [ ] Northern Ireland
- [ ] Other countries in European Economic Area

Total UK sites in study 1

Does this trial involve countries outside the EU?
- [ ] Yes
- [x] No

A72. Which organisations in the UK will host the research? Please indicate the type of organisation by ticking the box and give approximate numbers if known:

- [x] NHS organisations in England
  1
- [ ] NHS organisations in Wales
- [ ] NHS organisations in Scotland
- [ ] HSC organisations in Northern Ireland
- [ ] GP practices in England
- [ ] GP practices in Wales
- [ ] GP practices in Scotland
- [ ] GP practices in Northern Ireland
- [ ] Joint health and social care agencies (eg community mental health teams)
Local authorities
Phase 1 trial units
Prison establishments
Probation areas
Independent (private or voluntary sector) organisations
Educational establishments
Independent research units
Other (give details)

Total UK sites in study: 2

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)
☐ Other insurance or indemnity arrangements will apply (give details below)

See Appendix X for a copy of relevant documents
The University of Brighton is insured by Zurich Municipal, Policy number: NHE-17CA04-0043
Limit of Indemnity:
Public and Products Liability: Employers’ Liability: Professional Indemnity:
£ 30,000,000 for any one occurrence, with an excess of £1,000
£ 30,000,000 for any one claim inclusive of costs, with nil excess
£5,000,000 for any one claim or in any one period of insurance, with an excess of £2,500

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
☐ Other insurance or indemnity arrangements will apply (give details below)

See Appendix X for a copy of relevant documents
The University of Brighton is insured by Zurich Municipal, Policy number: NHE-17CA04-0043
Limit of Indemnity:
Public and Products Liability: Employers’ Liability: Professional Indemnity:
£ 30,000,000 for any one occurrence, with an excess of £1,000
£ 30,000,000 for any one claim inclusive of costs, with nil excess
£5,000,000 for any one claim or in any one period of insurance, with an excess of £2,500
Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

**Note:** Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- [ ] NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
- [ ] Research includes non-NHS sites (give details of insurance/indemnity arrangements for these sites below)

Participants will be recruited at NHS sites only.

Please enclose a copy of relevant documents.

---

### B. All research other than CTIMPs

**In this sub-section, an adult means a person aged 16 or over.**

#### B1. What impairing condition(s) will the participants have?

*The study must be connected to this condition or its treatment.*

This research project is specifically linked to people who have PMLD.

Mencap's PMLD Network defines the condition as "more than one disability, the most significant of which is a profound learning disability". People with PMLD are likely to have great difficulty communicating and need a high level of support (Mencap, 2012). Mencap also stresses the importance of participation in the arts in the lives of people with PMLD.

#### B2. Justify the inclusion of adults unable to consent for themselves. It should be clear why the research could not be carried out as effectively if confined to adults capable of giving consent.

People with PMLD are some of the most excluded in society (Mencap, 2012) and would benefit from inclusion in meaningful engagement; involvement in the arts has been highlighted as beneficial for this group (Mencap, 2009; DoH, 2011).

This study investigates how people with PMLD accessing inclusive arts interventions can inform the development of the meaningful engagement agenda. The qualitative data collected will be from this specific environment and will therefore be directly applicable to those with PMLD and their supporters. The same quality of research data could not be gained from a group where people did not have PMLD and therefore the research question would not be answered.

In order to investigate and disseminate ways in which people with PMLD can be best supported, it would be better for research to take place with people who have PMLD.

#### B3. Who in the research team will decide whether or not the participants have the capacity to give consent? What training/experience will they have to enable them to reach this decision?

The Chief Investigator will decide whether participants with PMLD have the capacity to consent. She has over 7 years experience in the field of disability arts. In this work she has gained experience in presenting information to people with PMLD and in assessing their understanding of it.

There will be no assumption made by the Chief Investigator that a person does not have the capacity to consent to participate in the research. Each person will be assessed in order to ascertain whether consent can be given as outlined by the Mental Capacity Act 2005.

#### B4. Does the research have the potential to benefit participants who are unable to consent for themselves?
If Yes, please indicate the nature of this benefit. You may refer back to your answer to Question A24.

1) This research will offer participants with PMLD an opportunity to gain from the stimulation, variation and challenges (Valks Kamp and Nakken, 1999) that working with visual arts provides. Specifically the research will look at the role of choice-making and how the expression of people's preferences within inclusive arts interventions can inform the development of the meaningful engagement agenda.

2) This research aims to contribute to the academic rigour and best practice in the field and thereby inform other practitioners who work alongside people with PMLD.

3) This research aims to contribute to the evidence base in the field by developing understanding around the role of the carer in the art-making process.

* It is felt that the benefits of this research outweigh the risks as outlined in section A24.
* Participants who wish to be involved in the research project will access the inclusive arts sessions within the regular timetable of the NHS Trust sessions thereby minimising any risk that the research might be considered invasive or intrusive. Those who do not wish to participate will continue to access regular Day Services as they normally would.

B5. Will the research contribute to knowledge of the causes or the treatment or care of persons with the same impairing condition (or a similar condition)?

If Yes, please explain how the research will achieve this:
The research aims to contribute to the knowledge base and understanding of best practice in the area of Inclusive Arts and PMLD. It aims to inform how we might support people with PMLD in choice-making and expression of their preferences in an Inclusive Arts intervention.

B6. Will the research involve any foreseeable risk or burden for these participants, or interfere in any way with their freedom of action or privacy?

If Yes, please give an assessment below. Highlight any risk, burden or discomfort specific to these participants and say what will be done to minimise it. You may refer back to your answers to Questions A22 and A23.

* The activities that participants will be involved in will be arts-based and although these may be new they will take place in familiar surroundings with the Chief Investigator and carers with whom there will also be familiarity. The arts activities have been designed to offer a range of choices at each stage so that burden to be involved in prescribed and limited activities will be greatly reduced.

* At all stages of the research project there is an opt-out route and all participants will be regularly reminded of this and supported to take it if they wish. Flowcharts representing this can be seen in Appendices X.

* During the inclusive arts workshops an area for relaxation and removal from the group will be available if participants express a need for it. Carers will work with the Chief Investigator to support participants to leave the room and will remain with the person until they are ready to return.

Questions B7 and B8 apply to any participants recruited in England and Wales.

B7. What arrangements will be made to identify and consult persons able to advise on the presumed wishes and feelings of participants unable to consent for themselves and on their inclusion in the research?

Consent to participate in the Research Project

The Chief Investigator will take the following steps:

* Identify a Consultee to advise if it is in the best interests of the potential participant to be involved in the research project.

* The Chief Investigator will meet with the Consultee and discuss the Information Sheet, answer questions and give
detailed information as requested. (Appendix X) She will also inform the Consultee that they can observe the research as long as none of the participants are affected by this.

* If the Consultee advises that it is in the participant's best interests to take part they will be asked to sign the Best Interests Form (Appendix X) However if they advise against this then the person will not be included in the research.

**During the Research Project**

Each participant will be accompanied by up to two participant carers who will remain with them during the course of the Inclusive Arts Workshops. These carers will be working regularly with the participant and be aware of their individual communication style including their assent and dissent positions and how they communicate these. These carers will be able to work with the Chief Investigator in the case of:

* The participant with PMLD is enjoying the activity.
* The participant with PMLD is not enjoying the activity.
* The participant with PMLD wishes to leave the room and have some time in a relaxation space.
* The participant with PMLD wishes to leave the research project.


*Please enclose a copy of the written information to be provided to consultees. This should describe their role under section 32 of the Mental Capacity Act and provide information about the research similar to that which might be given to participants able to consent for themselves.*

**B8. Is it possible that a participant requiring urgent treatment might need to be recruited into research before it is possible to identify and consult a person under B7?**

☐ Yes  ☐ No

*If Yes, say whether arrangements will be made instead to seek agreement from a registered medical practitioner and outline these arrangements. Or, if this is also not feasible, outline how decisions will be made on the inclusion of participants and what arrangements will be made to seek consent from the participant (if capacity has been recovered) or advice from a consultee as soon as practicable thereafter.*

**B9. What arrangements will be made to continue to consult such persons during the course of the research where necessary?**

N/A see above.

**B10. What steps will you take, if appropriate, to provide participants who are unable to consent for themselves with information about the research, and to consider their wishes and feelings?**

* The research study has been designed in order to ensure choice-making exists throughout the inclusive art sessions (Appendix X). Participants may prefer particular materials and other sensory stimuli and these wishes are considered key to the project design by directly impacting on the content of the subsequent workshop.

* The individual ways in which participants communicate their feelings will be closely monitored by the Chief Investigator and the participant carers present. No exercises, materials or methodologies will be used if a participant is showing disinterest, distress or any negative response. Choice making is key to the philosophy of the research design.

* Participants will be supported throughout the study to both leave the room in order to relax if needed (Section B6) or to opt-out of the study - this option will be highlighted and is an integral part of the research design (Appendix X).

**B11. Is it possible that the capacity of participants could fluctuate during the research? How would this be handled?**

It is unlikely that there will be fluctuation in the capacity of participants to consent as the condition is not one that fluctuates.

**B12. What will be the criteria for withdrawal of participants?**

The Chief Investigator and participant carers will look for the individual ways in which participants with PMLD show...
signs of distress in order to withdraw participants. B10 outlines this further.

The research Flowchart illustrates the option to opt-out at any time during the research study - Appendix X.

**B13. Describe what steps will be taken to ensure that nothing is done to which participants appear to object (unless it is to protect them from harm or minimise pain or discomfort).**

* The research study has been designed in order to ensure choice-making exists throughout the inclusive art workshops (Appendix X). Considerations to protect against objection or harm are further outlined in B10.

**B14. Describe what steps will be taken to ensure that nothing is done which is contrary to any advance decision or statement by the participant?**

People with PMLD will need lifelong high level care (PMLD Network, 2012), their cognitive impairment makes it unlikely that they will have made advanced decisions or statements.
**PART C: Overview of research sites**

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

<table>
<thead>
<tr>
<th>Research site</th>
<th>Investigator/ Collaborator/ Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institution name</td>
<td>Solent NHS trust</td>
</tr>
<tr>
<td>Department name</td>
<td>Kestrel Centre</td>
</tr>
<tr>
<td>Street address</td>
<td>Learning Disability Service, St James Hospital, Locksway Road,</td>
</tr>
<tr>
<td>Town/city</td>
<td>Portsmouth</td>
</tr>
<tr>
<td>Post Code</td>
<td>PO4 8LD</td>
</tr>
<tr>
<td>Title</td>
<td>Senior Occupational Therapist</td>
</tr>
<tr>
<td>First name/ Initials</td>
<td>Jo</td>
</tr>
<tr>
<td>Surname</td>
<td>Ball</td>
</tr>
</tbody>
</table>
PART D: Declarations

**D1. Declaration by Chief Investigator**

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
   - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
   - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
   - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
   - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
   - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee’s final opinion or the withdrawal of the application.

**Contact point for publication** *(Not applicable for R&D Forms)*

*NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.*

- Chief Investigator
- Sponsor

37
Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before the study starts for the research team to access resources and support. 

Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS Learning Disability Service, St James Hospital, Ball PO4 8LD 

I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

May be disclosed to the operational managers of review bodies, or the appointing authority for the REC. 

I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed. 

Signature: ....................................................... 

Print Name: Melanieia Warwick 

Date: 01/01/2014 (dd/mm/yyyy)

Access to application for training purposes (Not applicable for R&D Forms) 
Optional – please tick as appropriate:

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.
D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Signature: ............................................................

Print Name: .............................................................

Post: .................................................................

Organisation: ...........................................................

Date: (dd/mm/yyyy)
D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

<table>
<thead>
<tr>
<th>Academic supervisor 1</th>
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<tbody>
<tr>
<td>Signature:</td>
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<td></td>
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<tr>
<td>Print Name:</td>
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<td>Post:</td>
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<tr>
<td>Organisation:</td>
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<tr>
<td>Date: (dd/mm/yyyy)</td>
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</tbody>
</table>

<table>
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<tr>
<th>Academic supervisor 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Signature:</td>
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<tr>
<td></td>
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<tr>
<td>Print Name:</td>
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<td>Post:</td>
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<td>Organisation:</td>
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<td>Date: (dd/mm/yyyy)</td>
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<table>
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<tr>
<th>Academic supervisor 3</th>
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<tbody>
<tr>
<td>Signature:</td>
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<tr>
<td>Print Name:</td>
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<td>Post:</td>
</tr>
<tr>
<td>Organisation:</td>
</tr>
<tr>
<td>Date: (dd/mm/yyyy)</td>
</tr>
</tbody>
</table>
Dear

My name is Melaneia Warwick, I am a PhD student at the University of Brighton.

I am contacting you because I am hoping to carry out a piece of research looking at what people with complex needs might find meaningful in a series of arts workshops. The research has recently gained the ethical approval of the NHS.

As part of this research I am hoping to recruit a group of service users. I will be looking at ways of working with them and supporting them to have lots of choices through arts activities. If the person agrees to take part in the research I will work with them to make artworks and a collaborative film.

Myself, Jo Ball a Senior Occupational Therapist and a member of staff from New Road have been through a process of capacity assessment with each of the people that attend the project. This means we tried to find out if they would be able to understand what it means to take part in the research with me. We felt that ……… would not be able to understand this enough to make a fully informed decision. Therefore, under the law we must consult with someone else in her / his life who can help us make the decision about whether or not she / he should take part. We would very much like it if you could help us make that decision.

I have attached some information about the project for you to read, including an Information Sheet and Consent Form. These are written as accessibly as possible but you may have questions and I would be very happy to talk about the project with you further. I am hoping to meet with consultees on the 24th June 2014. If you are willing to take part, I wonder if you can meet with myself and Jo Ball at the New Road Day Centre to discuss further. We have not yet agreed times for this but if you can contact Janice Webb at the Day Centre she would be happy to arrange a time convenient to you on that day.

- janice.webb@portsmouthcc.gov.uk or by phone on
- 023 92 696783 or 07961931065

Thank you for taking the time to consider this.

Yours sincerely

**Melaneia Warwick**
PhD Research Student
University of Brighton
Appendix C  Capacity and Recruitment Forms

PMLD Participants
Assessment of Capacity based upon the Mental Capacity Act, 2005.

(Begin the process from the assumption that the person has capacity to make the decision in question).

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>DOB</td>
<td></td>
</tr>
<tr>
<td>Address</td>
<td></td>
</tr>
<tr>
<td>Date of Assessment</td>
<td></td>
</tr>
<tr>
<td>Names of people involved in assessment (MDT approach is essential).</td>
<td></td>
</tr>
</tbody>
</table>

Proposed Intervention:

Communication

How does this person communicate? (eg. Spoken language, Makaton, objects of reference, etc.)

How do they express “yes” or indicate “okay”?  

How do they express “no” or indicate “stop”?  

How does the person communicate that they do not understand, or do not know? (will they ask for help?)
<table>
<thead>
<tr>
<th>Can the person make their needs/preferences known?</th>
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</thead>
<tbody>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>What is needed to support this person's understanding of information?</th>
</tr>
</thead>
<tbody>
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<td></td>
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</table>

**Information sharing**

<table>
<thead>
<tr>
<th>Has the person been informed of the proposed intervention?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes [ ] No [ ]</td>
</tr>
<tr>
<td>If 'No', why not:</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How was this information presented and how did the person respond?</th>
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</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

**Decision Making**

Please ask the individual the following questions, recording all responses or acknowledging no response. Please use communication methods preferred by the individual when asking the questions.

**Question One**
- Can you tell me about the proposed intervention?
- What is going to happen?

<table>
<thead>
<tr>
<th>No response [ ] Response - please record:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

**Question Two**
- What would happen if you said you did not want this to take place? (consequences)

<table>
<thead>
<tr>
<th>No response [ ] Response - please record:</th>
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</table>
## PhD Research
M Warwick, University of Brighton

### Question Three
What are the benefits/good things of this happening? Is it going to help?

- No response

### Question Four
What are the risks/bad things involved in this decision? What are you worried about?

- No response

### Question Five
Is it okay to carry out this intervention?

- No response

---

### Determining Capacity

If person has answered questions 1, 2, 3 and 4 appropriately and demonstrated a basic understanding of the proposed intervention, then consent is valid and appropriate consent forms may be signed by the individual.

- **VALID CONSENT GIVEN**
- **CONSENT NOT GIVEN**
- **PERSON LACKS CAPACITY TO GIVE CONSENT TO PROCEDURE**

If person has shown no response to questioning or has not demonstrated a basic understanding of the proposed intervention, then consent is not valid as capacity is not present. This procedure must now follow the ‘best interest’ option.

**NOW FOLLOW THE BEST INTEREST PROCESS.**

The undersigned participated within this assessment and are in agreement with the final decision:

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(This assessment form has been based upon a document produced by Solent NHS Trust, 2007).
### Deciding on a participant’s Best Interest under The Mental Capacity Act, 2005.

(Please ensure the assessment of capacity form has been completed prior to commencing this form).

<table>
<thead>
<tr>
<th>Name of service user/patient</th>
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<tr>
<td>DOB</td>
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<td>Details of the decision</td>
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<tr>
<th>Is a best interest meeting needed?</th>
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<tr>
<td>Is there a valid and applicable advance decision covering this area?</td>
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<tr>
<td>Is there a valid lasting power of attorney or court appointed deputy? If so give details.</td>
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</table>

Form completed by
Date of completion

---

### Regaining of capacity

(Is it likely that the person will at sometime have capacity in relation to the matter in question? If so, when is it likely to be? Can the decision wait till then? If the answer is yes then wait until capacity has been regained and then proceed with a consent form) Details:

### Confirm you have followed the Best interest checklist:

Encourage participation, Identify all relevant circumstances, Find out the person’s views, Avoid discrimination, If the decision concerns life-sustaining treatment any action must not be motivated in any way by a desire to bring about the person’s death, Consult others, Take all of this into account (Code chapter 5)

<table>
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<tr>
<th>Yes</th>
<th>No</th>
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### How was the person encouraged to participate and how where their wishes and feelings established?

What are the person’s views, wishes and feelings both past and present, the beliefs and values that would be likely to influence their decision if they had capacity; and the other factors that they would be likely to consider if he were able to do so. What weight should they be given and why?
Who else in the person’s social network have you consulted, what are their views, what weight should be given to them and why? (As far as reasonably practicable and appropriate the following must be consulted anyone named by the person is someone to be consulted on the matter in question or on matters of that kind; anyone engaged in caring for the person or interested in his welfare; any done of a power of attorney granted by the person any deputy appointed for the person by the Court)

<table>
<thead>
<tr>
<th>Person</th>
<th>Relationship</th>
<th>View, weight to be given to it and why</th>
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What are the relevant circumstances in this case. List the factors to be considered, the weight to be given to each and why.

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<th>Circumstance</th>
<th>Weight to be given to it and why</th>
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</table>

What are the possible courses of action and likely outcomes. Include the effects of any restrictions that will be on the person and the effect/impact of NOT taking the course of action.

<table>
<thead>
<tr>
<th>Course of action</th>
<th>Positives of following it</th>
<th>Negatives of following it</th>
</tr>
</thead>
</table>
Weighing the above in the balance what is in the person’s best interest and why. Include why and how it is the less restrictive intervention possible.

What restrictions on the person will be involved in the implementation of this plan and how will they be kept to a minimum and reviewed?

If the plan involves residence or admission to hospital, does the cumulative effect of the restrictions amount to a Deprivation of liberty?  YES  NO

If the answer is yes the DOLS procedures need to be followed

To be signed by those involved in the process.

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
<th>Signature</th>
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<tr>
<td></td>
<td>Decision maker</td>
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</table>
My name is Melaneia.

I am a PhD student at the University of Brighton. I am learning about making art and with people who have profound and multiple learning disabilities.

I would like to invite you to be in my educational research project.

There will be 20 workshops. They will be at the Day Centre.
I am interested in finding out what kind of artworks you would like to make and what materials you enjoy using.

You will have the chance to learn about different art materials and decide what you like to do.

You will make your own artworks about these choices.

I hope I will learn more about what you like and how you can be supported to develop your own artworks.

We will have an exhibition at the end of the project where other people can see your artwork. You can take all of your work after the exhibition.
In the art sessions we will make a film and take photographs. You, your family and carers can see the film and photographs before anyone else to let me know if you are happy with them. No photographs or film of you will be used if you do not want them to be.

I will show the film and photographs to other students, artists or researchers like me. I will also show them to other carers. They will not be shown on a web-site or over the internet.

You do not have to do the project. It is your choice.

If you want to leave the project at any time, you will be supported to do so. No information or images of you will be used if you leave the project.

You can stop doing the workshops or project anytime you want to, it is your choice. If you want to stop you will be supported to leave the art room. You can decide if you want to come back or not.

You keep all of the artwork you have made in the project. I will not use any of the film or photographs with you in them if you leave the project.
If you have any question I can answer them or you can contact my supervisor Alan Tomlinson at the University of Brighton.
V.6 24th March 2014

Melaneia Warwick
c/o Hannah Landry
MA Inclusive Arts Practice
Faculty of Arts
University of Brighton
Grand Parade BN2 0JY
Telephone: 07540 377941
Email: M.Warwick1@uni.brighton.ac.uk

Professor Alan Tomlinson
Supervisor
University of Brighton
Grand Parade
BN2 0JY
01273 643223
A.Tomlinson@uni.brighton.ac.uk
Participant Consent Form

Please put your initial in the box above your answer for all the questions. This will let us know whether you want to take part in this PhD educational project and that you know what is involved.

I understand the dates and activities for this project

[ ] YES [ ] NO

I agree to take part in the research and in the activities in the timetable

[ ] YES [ ] NO
I have been given the Information Sheet and have asked any questions about the project.

I have met Melania and we have talked about the project together.

When signing this form I know I can stop coming to this project at any time.

Signed: .............................................
Name: ............................................... 
Date: ............................................... 

I have explained my project to the participant and given clear answers to any questions.
V.5 11th March 2014

Signed..............................................

Name..............................................

Date..............................................
Consultee Information Sheet

INVITATION PARAGRAPH

I would like to invite _____________ to take part in my PhD educational research study. It has been established that she does not have capacity under Mental Capacity Act 2005 to consent to taking part herself. I would therefore like to invite you as her Consultee to consider whether or not taking part would be in her best interests.

Before you decide I would like you to understand why the research is being done and what it would involve for ___________. This information sheet is particularly detailed due to the nature of the study and the importance of you fully understanding what ___________ will be participating in before you make your decision.

Part 1 of this Information Sheet tells you the purpose of this study and what ___________ will be involved in if she takes part. Please read Part 1 and then, if you are considering recommending participation, please go on to read Part 2, which will give you more detailed information about the conduct of the study.

I will go through this information sheet with you. Ask me if there is anything that is not clear and I will answer any questions you may have. Talk to others about the study if you wish.

PART 1

Study: How can adults with PMLD accessing an inclusive arts intervention inform an understanding of meaningful engagement in this context?

SUMMARY: This study concerns people with profound and multiple learning disabilities (PMLD). It aims to investigate the access of inclusive arts interventions by groups of adults with PMLD and how this access leads to insights that can support the development of the meaningful engagement agenda. I am also interested in how Carers can be supported to help their clients in the Inclusive Arts setting. I will be running an intervention consisting of 20 Inclusive Arts sessions at Portsmouth City Council Day Services, New Road Centre, as a way to investigate these questions.

WHAT IS THE PURPOSE OF THE STUDY? This study concerns people with profound and multiple learning disabilities (PMLD). The purpose of this study is to look at how access to inclusive arts sessions can inform the development of the meaningful engagement agenda.

* WHY HAS _________________ BEEN INVITED?

___________ has been invited because she is an adult (aged 18 or over) who has PMLD as described above who is attending the Portsmouth City Council Day Services, New Road Centre.

* WHY AM I INVITING ________________ WHEN SHE CANNOT CONSENT TO PARTICIPATE HERSELF?
is unlikely to fully understand the purpose of this study and the reason for being invited to take part. It is nonetheless important to invite her because:

We need to understand and gain insight into the experiences of people like _______ in order to understand how we can best support them. For ___________ to participate in research about her: what she enjoys and doesn’t enjoy, the choices she makes and therefore how her needs can be better met, means that we are taking an inclusive and focussed approach to research.

Only recruiting people who do have the capacity to consent would not answer the research question.

* DOES __________ HAVE TO TAKE PART?

It is up to you to decide whether it is in _______ best interests to join the study. I will describe what will be involved by going through this information sheet. I will give you plenty of opportunity to ask questions and clarify what will happen and why. Please consider the broad aims of the research, the risks, benefits and practicalities of being involved and whether you think ___________ would be content to take part or whether doing so might upset her.

I will not include ___________ in the study if you advise against this. If you agree that taking part is in her best interests, I will then ask you to sign a form to this effect.

* WHAT WILL __________ DO IF SHE TAKES PART?

___________ would attend 20 inclusive art sessions at the Portsmouth City Council Day Services, New Road Centre as part of her usual timetabled routine. She would be invited to be involved in art-making activities over these sessions. I will collect information and data on these sessions in the following ways:

• Documentation of the sessions using video and photography:
• Observations of ___________ making her artwork with her carers supporting her to do so;
• Feedback with carers before and after sessions;
• Structured evaluation and feedback from carers at the end of the workshop programme

If ___________ takes part, I will invite you to observe some or all of the sessions as long as this does not affect any of the other participants in the group.

Throughout the period that ___________ takes part in the study, I will keep in touch with you regularly. This will be particularly important to ensure that ___________ can participate in decisions and that I notice and respond to signs of objection (see also 2.1 below).

* WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?

The main disadvantage of ___________ taking part is the possible discomfort ___________ experiences if she does not enjoy any of the art-making activities. I do not think that the risk of this happening is high and provision is made for her to make lots of different choices about what she wants to do during the sessions. ___________ will also have access to a relaxation space if she wants to leave the art-making session.

* WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

The benefits of participation in the arts for people with PMLDs have been highlighted by Mencap’s PMLD Network.
V.5 11th March 2014

Although I cannot promise that __________ will directly experience these benefits from participating in this study, I hope that there may be indirect benefit to her. The study may:

- develop a clearer understanding of how to support people like __________ to participate in inclusive arts activities;
- develop some strategies for informing and training carers about inclusive arts activities;
- contribute to the development of the meaningful engagement agenda through the dissemination of a series of recommendations highlighting best practices;
- inform arts practitioners and other interested parties about what has been learned;
- contribute to the evidence base for this practice;

* Expenses and Payments

No expenses will be incurred by __________ as a result of taking part in this study.

* What if there is a problem?

Any complaint you may have will be addressed. The detailed information on this is given in Part 2.

* Will my taking part in the study be kept confidential?

Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1. If the information so far has interested you and you are considering recommending that it would be in __________ best interests to take part, please go on to read the additional information in Part 2 before making any decision.
PART 2

* WHAT WILL HAPPEN IF _______________ DOESN’T WANT TO CARRY ON WITH THE STUDY?

_________ may withdraw or be withdrawn from the study at any point, for example if it becomes apparent that it is no longer in her best interests to take part. You can decide this at any point and will not need to give any explanation if you wish to do so.

I will work closely with _________ carers, I will do as much as I can to enable her to participate in all decisions about her involvement, including for example whether or not the arts activities are acceptable to her. We will pay constant attention to her willingness to engage.

Taking into account _________’s individual ways of communicating, I will ask you to agree in advance examples of changes in her behaviour that might indicate distress or unwillingness. I will respond to such behaviour by inviting _________ to relax in another room or to opt-out of the study if that is preferable. I will make a decision in close collaboration with others, including you. Due to the nature of the study, it will not be possible to take out data collected up to the point _________ withdraws and the intention would therefore be to retain it in the study.

* WHAT IF THERE IS A PROBLEM?

If you have a concern about any aspect of this study, please ask to speak to me and I will do my best to answer your questions. Alternatively or additionally, you could speak to one of my research supervisors, whose contact details are at the end of this document. If you remain unhappy and wish to complain formally, they will be able to give you details of the University of Brighton procedures for doing this.

* WILL _______________ TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?

Some of the data I gather about _______________ will be personal data that could lead to risk of potential identification. This would specifically be audio and video recordings that will only be shown to a limited audience. This would be:

1) Other students and academics at the University of Brighton or at academic Conferences and professional meetings.

2) Care professionals, arts professional and students who might attend talks or workshops to learn more about what happened during this research project,

3) Other people with PMLD and Learning Difficulties who might want to find out what art making is like and decide if they would like to attend some workshops in the future,

4) People attending the final Exhibition about this project.

5) Policy makers and people working in ways that effect policy.

None of this data will be shown on a web-site or over the internet.
**V.5 11th March 2014**

This data will be kept strictly confidential and the procedures for handling, processing, storing and destroying this data meet guidelines for good research practice and all appropriate legislation:

- Data will only be stored on portable devices (for example my laptop computer, memory stick, or audio/video recorders) for as long as is necessary to transport it to a more secure location and it will be password protected and/or encrypted on such device.
- Data will then be stored on a computer at the University protected by a password known only to me.
- Data on paper will be stored in sealed envelopes in a locked drawer at my home, New Road site or at the University.
- Particular care will be taken regarding the security arrangements for audio and video recordings.
- Only my supervisors, carers attending the project, those helping with film-making and I will have any access to data (e.g. original video or audio recordings).

**WHAT WILL HAPPEN TO THE FINDINGS OF THE RESEARCH STUDY?**

I will write up the findings of the study for my PhD and hold an exhibition to show what has been made by participants of the research project. I also hope to present these findings at relevant conferences and to publish articles in journals. I will give you the option of receiving a summary of the findings at the end of the study and of receiving a copy of the project film.

**WHO IS ORGANISING AND FUNDING THE RESEARCH?**

This research is organised by me for a PhD at University of Brighton. It has been funded by a scholarship from the Arts and Humanities Research Council.

**WHO HAS REVIEWED THE STUDY?**

The research has been reviewed and approved by my supervisors and also by the University of Brighton Faculty of Arts Research, Ethics and Governance Committee and the NHS National Research Ethics Service.

**FURTHER INFORMATION AND CONTACT DETAILS**

If you have any questions, or would like further information about this study, please contact me as follows:

Melaneia Warwick  
PhD Candidate  
c/o Hannah Landry  
University of Brighton  
Grand Parade  
BN2 0JY  
01273 227133  
M.Warwick1@uni.brighton.ac.uk

If you are unhappy about any aspect of the study, you can contact one of my academic supervisors, or my programme lead, as follows:
V.5 11th March 2014

Professor Alan Tomlinson
Supervisor
University of Brighton
Grand Parade
BN2 0JY
01273 643223
A.Tomlinson@uni.brighton.ac.uk

Alice Fox
Supervisor
Course Leader – MA Inclusive Arts Practice
University of Brighton
Grand Parade
BN2 0JY
01273 643059
A.V.Fox@uni.brighton.ac.uk
Consultee : Best Interest Consent Form

Study: How can adults with PMLD accessing an inclusive arts intervention inform an understanding of meaningful engagement in this context?

This project is part of a PhD study. It will be recorded and shown to other people. The person that will use this information is Melaneia Warwick. She will show you a copy of this information before it is shown to other people and you will be invited to comment and request changes.

I have read the project information. Yes No

I have had the opportunity to ask questions. Yes No

I have been given a timetable with the dates and activities that ______ will participate in during the research. Yes No

I understand that I can make the decision for ______________ to stop participating in the research at any time. Yes No

Workshops

I agree that it is in ______________’s best interests to take part in 20 inclusive arts workshops that will involve other staff from the Portsmouth City Council Day Services, New Road Centre, as well as Melaneia Warwick. Yes No

Film and Photographs

I agree that it is in ______________’s best interests that Inclusive Arts sessions are filmed and photographed. Yes No

I agree that it is in ______________’s best interests that artwork he / she makes is used in an exhibition about the research project. Yes No
V.5 March 11\textsuperscript{th} 2014

I agree that it is in __________’s best interests for photographs and film of the Inclusive Arts Workshops to be used in ways that will be seen by other people and the public. This might include reports, exhibitions or at conferences. They will not be shown on web-sites or over the internet.

\textbf{Yes  No}

I am satisfied that I have been given sufficient information regarding the project and hereby make a decision in the best interests of [insert participant name] to take part.

Signed ................................................................. Date..........................Name.................................................................

The project has been explained to the Consultee and full and clear answers to any questions have been given.

Signed .................................................................Date..........................
Appendix D  

Recruitment Forms  

Care Staff Participants
University of Brighton PhD

Participant Staff Information Sheet

I would like to invite you to take part in my PhD educational research study. Before you decide I would like you to understand why the research is being carried out and what your involvement will be.

I will go through this information sheet with you and will be able to answer any questions you might have. Please feel free to talk to other people such as family, friends and other support staff before making a decision.

Part 1 of this Information Sheet tells you the purpose of this study and what you will be involved in if you take part. Please read Part 1 and then, if you are considering participation, please go on to read Part 2 which will give you more detailed information about the conduct of the study.

PART 1

PART 1

Study: How can adults with PMLD accessing an inclusive arts intervention inform an understanding of meaningful engagement in this context?

SUMMARY: This study concerns people with profound and multiple learning disabilities (PMLD). It aims to investigate the access of inclusive arts interventions by groups of adults with PMLD and how this access leads to insights that can support the development of the meaningful engagement agenda. I am also interested in how care staff can be supported to help their clients in the Inclusive Arts setting. I will be running an intervention consisting of 20 Inclusive Arts sessions at the Portsmouth City Council Day Services, New Road Centre as a way to investigate these questions.

WHAT IS THE PURPOSE OF THE STUDY? This study concerns people with profound and multiple learning disabilities (PMLD). The purpose of this study is to look at how access to inclusive arts sessions can inform the development of the meaningful engagement agenda.

* Why have I been invited?

The study is for people with PMLD attending the Portsmouth City Council Day Services, New Road Centre and for Staff.

* Do I have to take part?

If you are interested in taking part, I will explain what is involved and go through this information sheet. If you decide to participate, I will ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.
V.6 11th March 2014

* WHAT IS EXPECTED FROM PARTICIPANTS?

• You would attend a one-day professional development workshop on the Inclusive Arts setting and participate in some art-making activities. You would be invited to give your feedback and thoughts on this.
• You would be involved in 20 x 2 hour inclusive arts sessions at the New Road Centre, Portsmouth as part the usual timetabled routine. You would be support art-making activities over these sessions that will be filmed and photographed. You would be invited to give feedback on these sessions. Sometimes audio recordings of your thoughts will be made.

* WHAT ARE THE POSSIBLE DISADVANTAGES OF TAKING PART?

People who are uncomfortable in group settings may find some aspects of the workshop challenging. You will be supported to give anonymised feedback or not to say anything unless you want to.

* WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

I cannot promise that the study will help you immediately but the information gained may help to improve the support and quality of services available to people with PMLD in the future.

* EXPENSES AND PAYMENTS

You will not be expected to make any payments or incur any costs by participating in this study.

* WHAT IF THERE IS A PROBLEM?

Any complaint you may have will be addressed. The detailed information on this is given in Part 2.

* WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes part 1. If the information so far has interested you and you are considering participation, please go on to read the additional information in Part 2 before making a final decision.
* **WHAT WILL HAPPEN IF I DON’T WANT TO CARRY ON WITH THE STUDY?**

If you withdraw from the study, no further data will be gathered or recorded relating to you. However, I may use the information collected up to the time of your withdrawal.

* **WHAT IF THERE IS A PROBLEM?**

If you have concerns about any aspect of this study, you should first speak to the Chief Investigator (Melaneia Warwick) who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this via her co-supervisors at the University of Brighton, contact details at the end of this form.

* **WILL ____________ TAKING PART IN THIS STUDY BE KEPT CONFIDENTIAL?**

Some of the data I gather about ____________ will be personal data that could lead to risk of potential identification. This would specifically be audio and video recordings that will only be shown to a limited audience. This would be:

1) Other students and academics at the University of Brighton or at academic Conferences and professional meetings.

2) Care professionals, arts professionals and students who might attend talks or workshops to learn more about what happened during this research project,

3) Other people with PMLD and Learning Difficulties who might want to find out what art making is like and decide if they would like to attend some workshops in the future,

4) People attending the final Exhibition about this project.

5) Policy makers and people working in ways that effect policy.

None of this data will be shown on a web-site or over the internet.

This data will be kept strictly confidential and the procedures for handling, processing, storing and destroying this data meet guidelines for good research practice and all appropriate legislation:

- Data will only be stored on portable devices (for example my laptop computer, memory stick, or audio/video recorders) for as long as is necessary to transport it to a more secure location and it will be password protected and/or encrypted on such device.
- Data will then be stored on a computer at the University protected by a password known only to me.
- Data on paper will be stored in sealed envelopes in a locked drawer at my home, NHS site or at the University.
- Particular care will be taken regarding the security arrangements for audio and video recordings
- Only my supervisors, carers attending the project, those helping with film-making and I will have any access to data (e.g. original video or audio recordings).

* **WHAT WILL HAPPEN TO THE FINDINGS OF THE RESEARCH STUDY?**

I will write up the findings of the study for my PhD and hold an exhibition to show what has been made by participants of the research project. I also hope to present these findings at relevant conferences and to
V.6 11th March 2014

publish articles in journals. I will give you the option of receiving a summary of the findings at the end of the study and of receiving a copy of the project film.

* WHO IS ORGANISING AND FUNDING THE RESEARCH?
This research is organised by me for a PhD at University of Brighton. It has been funded by a scholarship from the Arts and Humanities Research Council.

* WHO HAS REVIEWED THE STUDY?
The research has been reviewed and approved by my supervisors and also by the University of Brighton Faculty of Arts Research, Ethics and Governance Committee and the NHS National Research Ethics Service.

* FURTHER INFORMATION AND CONTACT DETAILS
If you have any questions, or would like further information about this study, please contact me as follows:

Melaneia Warwick
PhD Candidate
c/o Hannah Landry
University of Brighton
Grand Parade
BN2 0JY
01273 227133
M.Warwick1@uni.brighton.ac.uk

If you are unhappy about any aspect of the study, you can contact one of my academic supervisors, or my programme lead, as follows:

Professor Alan Tomlinson
Supervisor
University of Brighton
Grand Parade
BN2 0JY
01273 643223
A.Tomlinson@uni.brighton.ac.uk

Alice Fox
Supervisor
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Study: How can adults with PMLD accessing an inclusive arts intervention inform an understanding of meaningful engagement in this context?

This project is part of a PhD study. It will be recorded and shown to other people. The person that will use this information is Melaneia Warwick. She will show you a copy of this information before it is shown to other people and you will be invited to comment and request changes.

I have read the project information.    Yes  No

I have had the opportunity to ask questions.    Yes  No

I have been given a timetable with the dates and activities of the research.    Yes  No

I understand that I can make the decision to stop participating in the research at any time.    Yes  No

Workshops

I agree to take part in 20 inclusive arts workshops that will involve other staff from the Portsmouth City Council Day Services, New Road Centre, as well as Melaneia Warwick.    Yes  No

Film and Photographs

I agree to the Inclusive Arts sessions I part in being filmed and photographed.    Yes  No
V.5 11th March 2014

I agree to any artwork or learning tools I create in the Professional Development Workshops to be used in an exhibition about the research project.

Yes  No

I agree to images of any artwork or learning tools I create in the Professional Development Workshops to be used in further Professional Development opportunities for others.

Yes  No

I agree for photographs and film of me to be used in ways that will be seen by other people and the public. This might include reports, exhibitions or at conferences. They will not be shown on web-sites or over the internet.

Yes  No

Audio Recording

I agree for audio recordings to be made of my comments during the project.

I am satisfied that I have been given sufficient information regarding the project and hereby make a decision to take part.

Signed .............................................................. Date..................... Name..............................................

The project has been explained and full and clear answers to any questions have been given.

Signed ..............................................................Date.....................
Appendix E  Peer Reviewed Book Chapter

Co-authored with Dr. Natasha Mayo
THE CERAMICS READER

Edited by Andrew Livingstone and Kevin Petrie
The title ‘Civic Ceramics’ refers to a growing number of practices that concertedly ‘shift the center of meaning’ from the artwork itself, to the activity of a viewer’s interaction, investment and sense of ownership over it. From work that explores the thematic overlaps in ceramics knowledge and studio skill base with its use in society, to practitioners employing ceramic practice as part of direct social engagement, the mapping of coordinates between ‘civic’ and ‘ceramics’ enables clear identification of a growing and increasingly innovative movement.

This essay attempts to uncover some of the approaches that are pushing ceramics to the forefront of participatory engagement. It also seeks to explore how we might better account for these emergent and diverse practices that are reawakening the discipline’s particular resonance as a politically and culturally responsive material.

Background

At a glance, it can appear that ceramic practice arose fundamentally in response to the need of society and then repositioned its profound material sensibility, technical knowledge and ergonomic concerns within more philosophical debate. In following this trajectory, any backward glance can be seen as a threat to what Jorunn Veiteberg describes as the ‘visibility’ of craft.1

The discipline was not however theoretically bereft before this point of departure. Historical reticence or ‘silence’ within the wider field of craft simply caused many of its concerns to be overlooked.2 The correlation between ceramics and society provides perhaps one of the field’s most integral and authentic debates.

The correlation of ‘Civic’ and ‘Ceramics’ equips us with both a framework for interpretation and a mode of practice for examining, at a more nuanced level, the boundaries of the ‘intervening space’ between the discipline and the community. More than this, it can enable us to identify practices that are creating a virtue of this previously opaque area, by pulling into view the unusual or simply forgotten connections that lie between the community and traditional and contemporary ceramic practices.

In fact, once an investigation of ceramics’ connection to a community is undertaken, any previous sense of their separation can become extremely difficult to maintain; from hair dressers’ straighteners to spark plug insulators, from catalysts to sensors, ceramics can be found almost everywhere you look and sometimes where you can’t. This connectivity persists in all manifestations of studio ceramics to a greater or lesser degree, offering potential dialogue to expand or deepen any imposition we might make upon its form.

It is not surprising therefore, that many high profile, international ‘gallery’ artist’s such as Clare Twomey, Stephen Dixon and David Cushway are developing respected practices engaging with dialogue that
reconnects ceramics with the community that shaped it. Participatory art is no-longer relegated to the margins. As Hal Foster states: ‘in the social expanse of everyday life, the possibilities for participatory art are endless’.3

Definition of terms

Before continuing, perhaps we need to more clearly define our terms when speaking of ‘participation’ in art. A common distinction is drawn between ‘Participatory Art Projects’, and ‘Participatory Art’ (per se). This distinction usually separates participation in contemporary art practices – such as events-based practice at biennales or contemporary gallery commissions, with social engagement-based projects – such as those working within public, community or socio-urban contexts, often sponsored by local government.4

Such distinction fuels the art as ‘social therapy’ versus ‘authentic art’ argument, the assumption that Participatory Practice is unable to withstand the critical evaluation of ‘art world’ critics, specifically because its value is lodged in the interaction between participants (and whatever products or benefits that brings) as opposed to the artwork itself.5 This is where the relationship between the artwork and its ‘point of meaning’ has been historically problematic.6

Whilst it is well understood that the artistic and cultural life of a society is heralded as a ‘barometer of its health’ the impact of art that speaks directly to or with society is often met with scepticism. This is in part due to the problem of measuring its transformative capacity; whilst elements of an ‘aesthetic encounter’ are historically and socially determined, it would be impossible to establish with any certainty the root cause. This in turn, has resulted in methods of critiquing such practice that rarely reflect the complexity of its ‘transformative rhetoric’ and instead fall back onto more basic arguments.

So what method of analysis should we apply to artists such as Twomey, Dixon and Cushway without omitting or trivializing the strident participatory aspect of their art? The nature of participation, as Kester suggests requires ‘new ways of thinking’.7

A more progressive approach to understanding the rise in participatory practice in the field of ceramics would be perhaps to question how these practices redefine or transform our understanding of aesthetic experience. And how do they challenge preconceived notions of the object of art?

Case studies

Let us examine dynamic examples provided by Keith Harrison and AJ Stockwell, both of whom engage with dialogue created by the overlap between studio and society. In ‘Michael Hamilton’, Harrison courts the absurdity that can be found in the life/art juxtaposition, appropriating domestic electrical systems and portable appliances to conduct live firings of Egyptian paste in a living room! This intervening space is also inhabited by Stockwell in ‘Bad Teeth’ (Figure 65.1) exploring replicated processes in conservation and dentistry. Stockwell creates video of dental paste being used to conserve a porcelain cup and runs it concurrently with the dialogue of a patient undergoing a procedure in a dentist chair.

The significance of these examples for contemporary ceramics debate is two fold: 1) the artists necessarily establish a thorough appreciation of the nature of both contexts in order to succeed in their assimilation of them, 2) the perimeters of ceramics vocabulary was necessarily stretched through its engagement with another field. For example, Stockwell’s recognition of the connectivity between use of porcelain paste in conservation and dentistry enabled a far wider exploration, as well as consolidation of her ‘expertise’ in ceramics process.
The same is true of Harrison's exploration of the sensory experience of firing when set in relation to the domestic sphere.

These artists are a new breed of ceramicists, with a plurality of skill base that extends far beyond their own studio in order to facilitate movement between personal and wider social concerns. Such artists are in fact offering living examples of a generative approach to ceramics practice, with projects necessarily responding to context and need as well as retaining concern with contemporary ceramics debate. The benefits for the ceramicist are multifold, extending their engagement with their social and physical environment and mapping previously unchartered areas of knowledge.

Harrison and Stockwell's respective practice undoubtedly widens our appreciation of the remit of ceramics but are we missing something richer contained within these examples by simply accounting for them through conventional methodology? My account tells us very little about the complexities and contradictions of the actual performance of the work. I have simply acknowledged the role of the artist in focusing our attention on certain hidden relationships or correlations in our routine lives so as to challenge our normative assumptions. The actual response of the viewer may in fact bear little or no resemblance to this schema. My conventional critique has of course abstracted the practice from its participatory element.

If participatory and collaborative art practices shift the center of meaning from the artwork, object or event, to public interaction or dialogic engagement, we must do the same in accounting for them. This must be the case particularly when dealing with projects in which the viewer or participant has the potential to reshape and transform the work over time.

A fuller account of Harrison's practice would address the actual rather than the hypothetical experience of participants in the project – the actual experience of entering the living room and the emergent awareness of both the familiarity of the firing methods and difference the work offers in regard its contextual and sensorial impact. To be inclusive of its participatory element would require me to be more attentive to 'agency and affect' – to ways in which the site prompts particular response. I would need to be more attentive to my own and other signals through language and utterance, gesture and movement.

In accounting for participatory arts practice Kester demands that the various contributing factors of a project be gathered together in order to understand how their varying proximities impact upon the meaning of the work and its impact on participants. He terms this engagement 'a field-based approach' whereby analysis arises from inhabiting a space for a substantial amount of time, with attention to the social conditions of space, discursive, haptic, and temporal rhythms of the events that take place there.
The assertion is a simple one, that any thorough analysis of art practice that engages with participatory elements, however marginal, demands in itself a level of participatory engagement to review. Here the theorist or critic becomes, in Kester’s terms, ‘a genuine interlocutor in the unfolding of a given work, rather than a gray (or perhaps more accurately, white) eminence.’ Participatory practice requires a far more nuanced understanding of how an artwork is received.

Traditionally art and art theory is monological; analysis deals with the transformation of materials and intent by an artist, received by the perceptual capability of a viewer – both according to a single consciousness. Once this process becomes social, the ‘aesthetic’ is considered more as a form of knowledge relevant and communicable amongst a collective, or spheres of understanding. Art practice becomes about the social articulation of aesthetic experience.

If we shift the center of meaning further still toward community based practice, we discover more about how appreciation of craft’s social, participatory nature might enable us to better critique ceramics practice in more general terms.

In ‘Transnational dialogues in contemporary crafts’ ceramist Stephen Dixon, along with other researchers from Manchester, worked with the people of Dhal Ni Pol, Ahmedabad, India, to address the decline of traditional Indian craft skills, in jeopardy through globalization and the speed of market development.

The group sought to raise local awareness of the Pol’s unique and endangered architectural and cultural heritage. They first documented their everyday rituals, then began to encourage a new daily ritual around a notional ‘doorway’, resulting in a series of ceramic installations, temporary site-specific artworks, films and events reflective of the particularity of Pol’s ‘social aesthetic’.

This new ritual was intimately connected to the Pol’s everyday and at the same time different, allowing objectivity and enabling the inhabitants to witness their own ‘social aesthetic identity’ emerging before them.

Conclusion

Whilst the center of meaning radically shifts in each example given in this essay, displaying variable dynamics between craft and its particular social community or constituency, each shift uncovers the discernable connectivity of ceramics to society. The Participatory aesthetic can be seen as returning craft to its origin but not merely by engaging with a community, it recognizes the capacity of craft to motivate exchange and cohesion between those who engage with it, both in regard to making and interacting with it.

Far from posing a threat to the academic vantage point of contemporary ceramics, this ‘backward glance’ in fact offers a potential means by which to articulate the potential of crafts aesthetic as something more powerful than traditional monological practices. The participatory aesthetic - as plural, fluid and open to risk - can offer us a means by which to better appreciate how craft contains forms of knowledge relevant and communicable amongst a collective, as opposed to remaining discrete and singular.

Notes

10. It's interesting to note how an aesthetic experience can become individualized and revealed through participatory practices, to the point where it has the potential to be 'owned and unique' as opposed to generalized and diluted as common perception may have it.
11. Irvine, J. The James Irvine Foundation, explores the various progressive stages of Participatory practice as follows: the official start of participatory arts, is referred to by Irving as 'Crowd sourcing' where the audience is involved in choosing or contributing financially to an artistic product - art exhibitions by community artists or theatre based on community stories come under this rubric. The second stage is co-production, and perhaps this incorporates AJ Stockwell if not in final production then in the pooling of knowledge and conceptual development. This stage often involves an exchange of creative energy between an arts organization and its public. Harrison's involvement of the public as both audience and completion of context also finds a position here.

The third and most participatory stage occurs when audience members substantially take control of the artistic experience. A professional artist may design the experience, but the outcome depends on the participants. Stephen Dixon and Clare Twomey's practice lies here.
'The persistent echo of the art/craft debate and a long dismissal of ceramics as fine art has caused an identity crisis. This is a remarkably full and timely account to start a dialogue of inclusion and diversity in the art world.'

SALVADOR JIMENEZ-FLORES, Artist in Residence at the Ceramics Program Office at Harvard University, USA

'An inspirational book that brings together informative and thought-provoking texts that explore ceramics from different perspectives and viewpoints. Invaluable for research, it will make a significant contribution to the discourse, encouraging dialogue and debate between students and academics alike.'

FELICITY AYLIEFF, Head of the Ceramics and Glass programme at the Royal College of Art, UK

'The Ceramics Reader is part seed bank, bedrock, reagent, and compass. Livingstone and Petrie have assembled an invaluable reference that so elegantly represents and agitates both historic and contemporary discourse in the field of ceramic art.'

BRIAN GILLIS, Associate Professor of Art at the University of Oregon, USA

'Bringing together a rich collection of critical texts, from ceramic luminaries such as Philip Rawson and Garth Clark to the provocative writing of a younger generation of practitioners, The Ceramics Reader is the book we have been waiting for.'

STEPHEN DIXON, Crafts Research Group Leader at Manchester School of Art, UK

The Ceramics Reader brings together key writings on ceramic art, craft and design. It focuses on debates from the last thirty years, but also gives the reader a broad overview of the last century. Texts have been chosen from a wide variety of sources, including books, magazines, journals and conference papers, as well as newly-commissioned material. The contributing authors are practitioners, critics, writers, curators, researchers and academics from around the world.

Andrew Livingstone is Professor of Ceramics and leader of the Ceramic Arts Research Centre (CARCuos) and Kevin Petrie is Professor of Glass and Ceramics and Head of Arts at the University of Sunderland, UK.
Appendix F  Peer Reviewed Journal Article

MELANIE WARWICK
University of Brighton

Shaping an NHS ethics application for research with people with profound and multiple learning disabilities: Creative strategies from a participatory arts practice

ABSTRACT
The call for the inclusive participation of adults with intellectual disabilities in research has been taken up by an emerging literature advocating the same opportunities for people with profound and multiple learning disabilities (PMLD). Yet, the barriers to researchers engaging with the demands and particular characteristics of the NHS ethical approval processes are well rehearsed. This can contribute to the marginalization already faced by people with PMLD, with the associated risk that the group remains under-researched. This case study explores current participatory action research utilizing inclusive arts techniques with people with PMLD. It suggests that despite the challenges, engagement with the NHS research ethics processes can be framed not as an isolated form-filling exercise but as a reflective device presenting an ongoing opportunity to gain multiple perspectives on a proposed

KEYWORDS
PMLD
inclusive research
participatory arts
NHS ethics
evolving consent
project. It offers possibilities to collaboratively shape inclusive research design and develop an evolving consent process. It identifies the creative strategies that have contributed to successful ethical approvals and the subsequent participation of people with PMLD in cultural activities.

CONTEXT

There is an emerging interest in how researchers can work with people with profound and multiple learning disabilities (PMLD). Mencap has described people with PMLD as having ‘more than one disability, the most significant of which is a profound learning disability … (and) additional sensory or physical disabilities, health and mental difficulties and difficulty in communicating’ (2013). The charity highlights the high level of support people will need in most of their daily lives. People with PMLD are a growing population expected to number 22,000 in England by 2026 (the population numbered 16,000 in 2010), and despite some perceptions that they are ‘not fully human’ (Mansell 2010: 7), people participate in and enjoy activities, form relationships and can often learn to ‘use equipment to express at least one important message’ (Mansell 2010: 8). There is a well-developed framework for gaining ethics approval in order to ensure that safeguards are in place prior to conducting research with people who lack the capacity to consent, and also proposals must be submitted to the National Health Service Research Ethics Committee (NHS REC) for consideration.

The NHS ethics approval process is based on the completion of an online application called the Integrated Research Application System (IRAS). Engaging with the NHS ethics approval process requires careful planning of the project timescales and represents a fairly imposing administrative burden. There is a decision-making window of up to 60 days for the completed, often lengthy applications: my own ran to 15,000 words. The IRAS form is framed within a medical and scientific research model and the prevalent research culture can be seen in questions such as ‘what is the scientific justification for the research?’ (2013: 5) and ‘give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol’ (2013: 8). There is an interesting bias in the latter question that highlights some of the presumptions around research relationships and throws a spotlight on traditional hierarchies of power (Nind 2014). Unsurprisingly, there is a discourse that positions RECs as increasingly conservative, restrictive bodies not only because of the obvious administrative burden they present. The ‘paternalistic stance’ (Iacono 2006: 173) taken by the ethical approval committees may be inadvertently restricting the opportunities of people with PMLD to self-determination and may be acting in a way that could be considered ‘exclusionary and discriminatory’ (Iacono 2006: 176). They may be dissuading researchers to steer away from studies with people who lack the capacity to consent, with an associated risk being the ongoing under-representation of people with high support needs in the literature. In addition, the perceived paternalism of the NHS REC process clashes with the aspirations of some writers to develop creative research methods (Nind 2013). For Boxhall and Ralph, the inclusion of image-based research approaches such as video may exacerbate a REC’s concerns about protecting the anonymity of vulnerable participants: ‘concern is raised about the possibility that tighter ethical regulation … combined with the multitude of ethical issues raised by the use
of image-based approaches may be discouraging the use of creative visual approaches in intellectual disability research’ (2009: 45).

**A CALL TO ARMS**

Despite these criticisms and the challenges presented, there is an emerging literature that is encouraging researchers to work towards developing creative methodologies in projects requiring NHS ethics approval. As Nind proposes, ‘good research is also research that is not frightened to go near people with high support needs’ (2013: 3). Other writers have also made claims to inclusion, stressing the importance of keeping the door open for people to participate in research and positioning this as a right of citizenship (Aman and Handen 2006; Ramcharan 2006). In her assessment of ethics committees in Australia, Iacono turns the tables on the protectionist argument noting that preventing people from participating in research ‘might be considered exclusionary and discriminatory’ in itself (2006: 176). Boxhall and Ralph extend the idea by prompting researchers to consider how this perspective can be communicated to the ethics committees:

> We would argue that the research community has a moral obligation to encourage research methods which include rather than exclude people with more severe intellectual disabilities. A further obligation is to increase ethics committees’ awareness and understanding of the implications of excluding people with profound and multiple intellectual disabilities from research. (2009: 51)

In my study, I would be utilizing creative research methods, particularly video and photography, with people who might lack the capacity to consent to participate. As this would imply challenging traditional views of research (Stalker 2010; Nind 2014), including the protection of anonymity (IRAS 2013), a strong case would have to be made to an NHS REC. In attempting to overcome the potential barriers this might present, I sought a way of balancing the demands of writing within a restrictive framework while maintaining the integrity of my practice. I went about shaping the application by drawing on my own participatory arts approaches.

**SHAPING THE APPLICATION: CREATIVE CONSULTATION**

Writers have highlighted the potential of video as a tool for giving voice, increasing the visibility of people with learning disabilities, and enabling them to express and others to gain insights into what their views might be. Additionally, where people have complex disabilities and are communicating non-verbally, video can be a powerful way for the researcher to conduct deep data analysis. Rojas and Sanahuja’s assessment of video as a vehicle for people with learning disabilities to convey their experiences shows how the researcher can gain a complex view of the participant’s experience. They advocate for people to have access to opportunities to convey their worldview, stating, ‘persons with severe and complex disabilities have beliefs, visions, opinions, points of view or ideas about the world around them, and therefore their subjective experience must be considered and valued’ (2011: 32).
As stated above, I was making a case for filming and photographing research participants and knew this could present concerns to the NHS REC. I had noted, though, that committees wanted researchers to show where they had consulted with the public on the shaping of the project. Combining my argument that film can provide a powerful tool for self-representation and self-advocacy with the consultation impetus, I arranged to meet with a group of learning disabled artists. I would pre-empt through conversation with this group of the questions the NHS REC might have about the research constituency I hoped to work with.

I visited the artists in their studio environment where they were making work for a visual arts show. The approach I took in the consultation was modelled on my participatory arts practice: utilizing a corner in the room, I set up a creative hub where a video camera and a digital voice recorder could be seen and explored. I introduced the project to the group by way of the equipment in order to provide visual cues for those who might need support in orienting themselves to the questions that would follow. The equipment could also be picked up, explored and its mechanisms explained if they were of interest to the artist, and so provided a focal point for exchange and dialogue. I wanted to examine what this group of artists thought about being filmed and photographed while making their artwork, and about any subsequent exposure of these outcomes to audiences that they both knew and did not know. Over a break in the artists’ studio activity, we engaged in semi-structured conversations; the six questions I asked and some of the conversations we had are included below:

**QUESTIONS**

1. Is making art important to you?
2. What is important about it for you?
3. How do you feel about being filmed and photographed when you are making your artwork?
4. What might people think about seeing you in a film or in a photograph making art?
5. How do you feel about people who don’t know you seeing you make your artwork in a film or photograph?
6. What do you think about using a video camera to record art making?

**CONVERSATION 1**

- **What might people think about seeing you in a film or in a photograph making art?**
- They might want to look at it and watch it, you know? It will give them loads of experience in case they want to do something like the same.

**CONVERSATION 2**

- **How do you feel about people who don’t know you seeing you make your artwork in a film or photograph?**
- I feel proud really.

During this conversation the artist expressed an interest in learning to control the Dictaphone, and we were able to continue, first, with her instructing me when to turn it off and then to controlling the off function herself. She was clearly focused in this task and reflected that she had enjoyed it.
CONVERSATION 3

- What do you think about using video to record art making?
- I would like to make a film one day.
- What would you like to make a film about?
- My printmaking.

These comments highlight the potential that engagement in arts activity held for this group both in terms of self-advocacy and as a vehicle for artists to pass on their skills and learning to a broader audience. The conversations might have been abstract without the equipment on hand as a point of reference; it seemed to facilitate richer dialogues than might otherwise have been had including one artist’s aspirations to make his own film in the future. It was, in addition, very interesting to note that the tables were turned on the traditional interviewer-interviewee relationship when control of the Dictaphone was in the hands of the artist; such shifts in power are rich sites for self-advocacy for people with learning disabilities and can offer learning opportunities for the researcher. The conversations gave weight to the arguments I was developing in the IRAS form such as the risks that people could face from being excluded including the opportunity to self-advocate via a creative practice.

SHAPING THE APPLICATION: A RECIPROCAL SHARING DAY

Mansell and Beadle-Brown have observed that the staff working with people with PMLD play a critical part in supporting them to fully access activities: ‘for people with severe and profound intellectual disabilities receiving services, it is axiomatic that in many respects, their quality of life depends on support provided by staff’ (2012: 13). For each of the participating artists in the study there would be one or two accompanying members of staff from the Day Centre. This group of staff would contribute to the data set being collected, requiring them to formally consent to take part in the project. Consequently, they would be taking on quite complex roles as participants, supporters and co-researchers.

I wanted to ensure we built the capacity for staff in terms of participatory arts approaches and increased their familiarity with a range of tools and materials. In addition, they would be invited to consult on the staff-specific consent and information sheets required by the NHS, support my development of knowledge about participants and help with my orientation to the setting. In keeping with my participatory action research methodology, the expertise and opinion of the staff would inform the project design and support an inclusive approach to the study. In order to facilitate these objectives and to start the formal recruitment drive of the staff into the project, a learning day was planned. Alongside building the capacity, I hoped to learn as much as I could about the ways in which staff thought we might work together. In this way I could use the IRAS form to evidence a commitment to creating a rigorous collaboratively informed project design that put people with PMLD at the heart of the study. This de-emphasis on traditional research hierarchies (Nind 2014) began with us naming the day ‘a reciprocal sharing day’.

The framework for the day was developed around three phases: orientation, material exploration and project development. I began with a range of stories and photographic images from my practice in order to share previous positive outcomes and challenges as well as aspirations for the developing research study. These stories acted as doorways into comment and conversation, were an opportunity for staff to ask questions and helped to develop a sense
of shared purpose for the group we would be working with (Walmsley and Johnson 2003). Additionally, my own questions to staff illustrated the inevitable gaps in my knowledge and evidenced my wish to work with their expertise.

It was interesting to note staff preconceptions around ‘good’ and ‘bad’ art and we set out to explore and challenge these through a series of art-making activities utilizing the materials I had planned as starting points for the workshops. I was able to address process in these activities and in particular engage with the staff in discussions about the value that an emphasis on self-creation might have for participants over more traditional co-creative approaches such as hand over hand. The act of sitting together and making artwork provided some important experiential learning and a site for reflection on ownership of process and final creative outcomes.

In the last phase of the day, I introduced a series of slotted cards that would support the group to work together to state and organize priorities for the creative workshops. This activity held a metaphor of building together and allowed us to see where common interests lay; in this way we discovered that planning and communication were commonly held as important factors of the project. Through these discussions we were able to work towards a better understanding of what staff roles would involve at the workshop stage of the project.
Figure 2: Reciprocal sharing day – project development, photo: Melaniea Warwick.

Some of the comments that came out of the consultation process on information and consent sheets gave me a closer understanding of the context for the study:

COMMENT
Where you’ve used ‘carers’ you might want to add in brackets, staff. Because we think of carers as being the family. For us it would be a helpful change.

I had used different terminology in a previous research setting and this comment helped me to more appropriately refer to people who would be involved in the current study.

COMMENT
We do have the highest amount of suitable people here, so we may as well run it here as long as other Centres don’t think we are grabbing everything for ourselves.

This useful comment helped to shape the design of the project, locating it at a particular Centre and giving me a broader perspective on the issues that might be impacting on Day Services in that area.

COMMENT
It does sound really interesting ... it’s nice just to know something a bit different is coming in.

The third comment came from a member of the staff and was echoed by others in the room. It illuminated the buy-in that the project was getting from those who would be supporting people with disabilities to access it.

COMMENT
Is that really your title? The Chief Investigator? It’s very Midsomer Murders!
Researchers applying to NHS RECs are obliged to adopt the title ‘Chief Investigator’, a term that might negatively impact on the attempts to flatten traditionally perceived hierarchies of power. However, use of humour can be one way to demystify the study, assisting partners to understand and buy into it. This comment defines a point in the day where the beginnings of positive working relationships began to emerge in the form of shared laughter.

From the comments collected at the end of the day, the following draw attention to the sense of potential felt by the group:

**COMMENTS**

*Made me look at ars with service users in a totally new way.*

*We will hopefully achieve great outcomes and promote individuality!*

**CONCLUSION**

The study I am conducting is built on participatory, creative approaches. It uses a range of tools including film and photography to provide new opportunities to participants to capture and share their experiences. Weaving opportunities for reciprocal learning and consultation into the development of the IRAS form allowed me to shape an application that was in the spirit of a participatory action research methodology. It advocated for people with PMLD to be engaged in research, highlighted some of the potential benefits and included the voices of people with learning disabilities, Day Centre support staff and managers. However, the current ethics approval process is not an ideal fit for arts practices and has received criticisms about its seemingly inflexible position. Hughes, in her critique of RECs in Macfarlane, identifies ethical practice as a continuous thread of activity that runs through the variant phases of her work ‘rather than something delivered by a signed consent form or adherence to a static set of principles’ (2009: 26). Yet, Boxhall reminds us to look at the opportunities for creating more informed RECs. She observes that engaging in research can be a positive experience for some of the people we are hoping to work with, and that we have a role in conveying this to the ethics committees, ‘it is important for ethics committees to stop people being hurt by research. But they also need to know the positive things that can happen for people with learning disabilities who get involved in research’ (2010: 173). I developed my skills as a researcher by engaging with this level of ethical approval by adding new dimensions of creative and critical thinking to the study design, especially where I was being asked to consider barriers, risks and challenges in ways that I may not have otherwise done.

Studies attempting to include people with PMLD make it clear that this is an under-researched group that faces the risk of remaining so. In applying for NHS ethics approval it is critical that researchers take every opportunity to consult on and co-create working approaches with disability groups, support staff and key stakeholders in order to maximize the involvement of people with PMLD in research.

**REFERENCES**

Aman, M. G. and Handen, B. (2006), ‘Reactions to ethical challenges and complexities of including people with intellectual disability as participants


**SUGGESTED CITATION**


**CONTRIBUTOR DETAILS**

Melaniea Warwick is a Ph.D. candidate in the College of Arts and Humanities at the University of Brighton undertaking practice-led research. Her thesis is entitled ‘Participatory arts and meaningful engagement for adults with PMLD’. The study is being conducted with a group of adults and their care staff and is based at the New Road Day Centre in Portsmouth. She successfully gained NHS ethics approval in April 2014.
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Exhibition Review

Marina Abramović: In Residence, Kaldor Public Art Project, No. 30. 24 June–5 July 2015, Pier 2/3 Walsh Bay, Sydney, Australia

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Appendix G  Atlas.ti Network Views

Hayley
Rob
Charlotte (1 and 2)
Dani
Sharon (1 and 2)
1 Meaningful Engagement - Friendships 1

10 Meaningful Engagement - Relationships

14.1 I asked if she wanted to help Josh make a picture, she jumped up and started talking to Josh and...

14.2 What was meaningful to the artist today? Watching the film that she recorded hearing her voice on...

14.4 [This comment was written by Hayley's mum Liz] I was amazed Hayley took no notice of me when she s...

16 Meaningful Engagement - Relationships 2

PD Workshop No. 5
Date 16/05/2014
Staff name Chrisy
Artist name Hayley
In this finished piece the depth of the charcoal means that Rob's fingers touch the bottom of the dish. I added more charcoal in subsequent weeks in order to ascertain whether the masks would be different.
Supporting Charlotte to use both hands to create two separate canvases at the same time (in pairs). Charlotte seemed to be highly focused and engaged.

Completed works: Left hand at top, right hand at bottom.

Charlotte holding charcoal stick independently for the first time. She subsequently used it to mark make on the first of the dried canvases in Week 7.

Charlotte’s first work on canvas. The support holds the marks well. Very small scale 7x5 inch.
Appendix H  Photo Thesis

Hardback book bound into thesis.
Appendix I  Process Films

DVD bound into thesis.