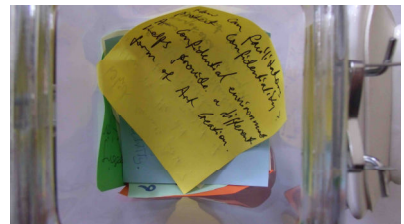
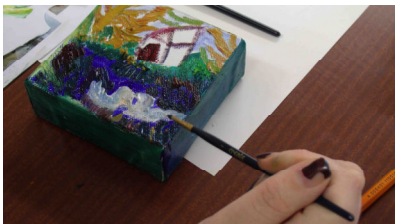


Confidentiality, Consent and Decision Making in Arts and Health Participatory Art Practice



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2 Abstract

The area of Participatory Arts is an innovative one, where artists can work with healthcare professionals and together look at the priorities of each profession in order to implement an effective programme. This study will look at consent, confidentiality and decision-making in this interaction. In doing so areas discussed will include: artist's responsibility; who has the final say in consent; disclosure of identity and what is art? Areas of crossover within the perspectives will be seen through: dignity of participant; processes of informed consent; clarity of intention and use of guidelines.



3 Introduction

‘Arts and health embraces a range of arts practices occurring primarily in healthcare settings, which bring together the skills and priorities of both arts and health professionals. Good arts and health practice is characterised by a clear artistic vision, goals and outcomes. It aims to promote health and wellbeing by improving quality of life and cultural access in healthcare settings.’¹ Ongoing dialogue between parties involved in Arts and Health will influence continual review of present guidelines.

Diversity of arts participation practice has implications for confidentiality, consent and decision-making. Arts and Health has a richness of strands making up this context including acute hospitals, community health, out patient clinics and long-term care crossing over different areas in healthcare. For each strand there is a separate context with its own considerations to be taken into account, while the diversity of artists’ methodologies adds another dimension to the area.

There is a crossover of points of discussion among the diversity of areas. Throughout the course of my research artists and healthcare professionals identified with the importance of dignity of a participant, consent as a process which is fully informed and the need to refer to guidelines that are in place. The Arts Council’s Arts and Health policy and strategy² should be consulted along with their guidelines for Sole Practitioners. Participatory Arts Practice in Healthcare Contexts Guidelines for Good Practice by Waterford Healing Arts Trust and Health Service Executive South (Cork) Arts and Health Programme supported by the Arts Council are also resources that were developed through a process of consultation with a representative group of practitioners in Ireland. The guidelines are intended as a platform for ongoing dialogue and debate around promoting best practice.

In this project’s study of participatory practice I feel it is important to identify that I have not included or addressed the participant’s voice as part of the research. I am addressing this conversation from an artist’s practice

¹ <http://www.artscouncil.ie/Arts-in-Ireland/Arts-participation/Arts-and-health/>

² http://www.artscouncil.ie/uploadedFiles/Arts_and_health_policy_2010_2014.pdf

perspective. I feel that in further discussion on this area the participant's voice would be an essential perspective to lend to the development of a full overview of those involved.

4 Methodology

This project is a qualitative analysis. A different kind of survey may have found different results. To my knowledge this is the first study in Ireland that specifically addresses, issues of confidentiality, consent and decision making.

One of the main objectives of this project was to consult with artists who work in an arts and health context and use participatory methodologies in their practice. This field is diverse in its settings, contexts and methodologies. Within these project workshops some of the artists attending are working freelance within a hospice, others are artists working in a coordinated programme in wards of an acute and community hospital. Peer dialogue workshops were held in four locations: West Cork Arts Centre; National Centre for Arts and Health AMNCH; Nazareth House Sligo; Cork University Hospital - which was the venue for a concluding workshop where there was an opportunity to validate project findings.

Initiating individual conversation with Healthcare Professionals was the second main objective. This led to healthcare professionals questioning their own perspectives about confidentiality, consent and decision-making in relation to participatory art. Within this dialogue three focus areas were taken considering the specific demands and circumstances of Mental Health; Alzheimer's and Oncology contexts.

The people included in these conversations were: Clinical Oncologist; Clinical Nurse Manager working in Oncology and Haematology; staff nurses; Consultant Psychiatrists; a clinical director; Community Psychiatric Nurse; Project leaders and Co-ordinators within the area of Alzheimer's. I held interviews and conversations which contribute to the development of this documentation. Quotations recognised within this work were gained with the consent of each person in question, while the main content of this work created from conversation has been presented anonymously.

I gained the view and perspective of Arts and Health Co-ordinators through individual conversations in addition to these workshops. Presenting project findings to a meeting of Arts and Health Co ordinators Ireland is my third objective.

My participatory practice was given the opportunity of development through an art project undertaken in a Mental Healthcare setting that was used to reflect on my current practice. My findings from this influenced piloting

participatory arts into a new space within an Oncology setting. As part of this work my studio practice has also developed, as a visual artist I felt led to create an artist's response to my findings.



5 Confidentiality

As an artist working within an Arts and Health context there is a responsibility to those that you encounter. Meeting with someone in what could be a vulnerable space, they are placing a trust in you as a person and in your profession. This obligation should be treated with the respect it is due while working with each person as an individual.

5.1 Mental health

5.1.1 Artists' perspective

While an artist would need to be made aware of anything that may affect the safety of the participant or workings of the group, their role within the service is not part of the clinical team. There would be no need that a person's file or diagnosis be disclosed to the artist, protecting someone's confidential medical information. If patients disclose information themselves an artist's place is still to respect their confidentiality. As an artist it is understood that the participatory group is confidential and what is said in a session will not be shared or disclosed to anyone outside of the service, as in any health setting following best practice guidelines. Unless otherwise stated sharing with the clinical team within a service would not be viewed as breaking confidence. A confidential environment helps provide a different form of art creation. This kind of space allows for open expression and experimentation with art.

At the beginning of a session or a project the group's boundaries would be acknowledged. These are especially important when someone who is unwell may be elated or their full cognition impaired and they may have no inhibitions in sharing more than they may do so otherwise if they are well. Participants know there is a need for respect of one another in the group, giving everyone a chance to participate to the level they feel prepared for in that session.

Within the curation of artwork that is made, there will be confidentiality issues to consider. A participant who has created work and has consented to the exhibiting of this artwork will be asked to think about whether they will be naming their work or labeling it as "anon". Either way it's important to acknowledge the achievement they have made by having it exhibited appropriately. Some artists suggested that in naming a work a participant would be encouraged by their achievements. Other artists made the point that

someone may create a work when unwell and consent to the work being exhibited, while at a later date may not remember what they created or not want what they made at a time they didn't feel well themselves to be on show. An artist seeking consent in curation of work should be sensitive to the participants' position both before and after receiving treatment

Artists discussed what the impact of family or institutional influence had on the participatory work when it came to curation and dissemination. In sharing of artwork made through participatory work, confidentiality is important to the participant but may also be something that the family members are interested in having an input at times, in care of their loved ones. Stigma that can at times unfortunately be based around Mental Health still in Ireland today may influence these decisions. While another consideration artists looked at was, "How is the art protected?" for a participant in a case where others influence the curation or the non curation of this work. The ownership of the art lies with the participant in what they have created. Curation of work within a health setting obviously needs to be appropriate but the question of censorship of someone's art is another complex area, which needs to be cautiously dealt with.

5.1.2 Healthcare professionals' view

Healthcare professionals voiced the need for an artist to have an awareness of their responsibility when curating work. Artwork containing personal content on display may raise issues. Work made in an art session, may be an expression of self and may be made when someone has limited inhibitions, and when they are well they may want more control over their expression. The artist would need to be aware of not breaking confidentiality if work were to be shared in an exhibition in the hospital space or a public viewing.

"Art sessions in mental health settings often have a therapeutic dimension, even when this is not the main aim. Such sessions can be a 'safe space' where the person can create, reflect and find a sense of peace. When an artist looks at curation of work for an exhibition which may have a public forum, she/he has a responsibility to revisit the sharing of work with a participant when are well. Private material can be shared with the artist working in mental health settings, as it can with doctors, nurses and other workers and so there is a responsibility on the artist to treat the work created in these settings with a great deal of care and respect. Some patients may not want their work to be

displayed.”³

5.1.3 Arts Co-ordinators’ view

There are no other practices that are so diverse with so many strands as Arts and Health. Working in the community you are meeting people who are there voluntarily. They are brave coming into a new setting, making the choice to attend a group. A group within the community shouldn’t be stigmatised but in saying that confidentiality is as important here as any other setting.

Confidentiality could be defined as: ‘The obligation to protect a patient’s right in respect of their anonymity, personal identity and health status.’

"In my understanding, confidentiality is an active thing, not simply a list of dos and don’ts. It's a commitment to the autonomy of a patient (or ex-patient) to withhold or disclose information with respect to their own health status and identity. Even within the healthcare environment this can come into play, as information might be shared on a need to know basis."⁴

5.2 Alzheimer’s

5.2.1 Artists’ perspective

When working with people whose cognition is impaired due to an illness such as Alzheimer’s it is important for an artist to have a clear conversation with the participant. The process of open conversation during the project will support how their consideration’s in the disclosure of diagnosis will influence the exhibiting of work that reveals their identity or not. This process can be done in consultation with the Healthcare professional as appropriate, with the emphasis on maintaining dignity at all times.

Artists raised experiences when families or institutions influenced the decision of confidentiality due to their concern of the artworks content or presentation. This led to a conversation on stigma’s effect on a family’s input on confidentiality or the simple right to maintaining their loved one’s dignity, a

³ Dr Pat Bracken. Clinical Director, West Cork Mental Health Service

⁴ Niamh O'Connor. Artist / arts and health coordinator

dignity in who they are and what is created which may affect the memory of them or their legacy in their community.

5.2.2 Healthcare professionals' view

Confidentiality for some was not the concern; the issue in their view was around disclosure of diagnosis. A healthcare professional spoke of having an awareness of people's diagnosis and their right to talk about it or not as they wished. From consultation with a number of professionals, there is a sense of frustration of lack of education causing stigma, which in their view needs to be addressed.

5.3 Oncology

5.3.1 Artists' perspective

On an artist's arrival in a day or long stay ward they will through their introduction learn a name, a bed or ward number of the patient. In some setting this will have been assisted by the healthcare professional as they are recommending someone for involvement or there has been a request from the patient for being involved in the participatory art. Artists will often have signed a contract of confidentiality, but in this initial amount of information confidentiality for a patient is protected.

In participatory art the participant will always need to be consulted. They make the decisions around their personal confidentiality, including their right to openly disclose their diagnosis or not. This needs to be considered when there is any question of them being identified through their work whether in exhibition or documentation. The artist has a place to reassure participants that they have a safe space to create.

5.3.2 Healthcare professionals' views

Some healthcare professionals saw no confidentiality issues arising when an artist begins working within a co-ordinated programme because they would have signed a contract of confidentiality and understand the terms and conditions of this in their work within that setting. Working freelance an artist also understands this and there are guidelines in place including an HSE document; 'Service Provider Confidentiality Agreement' ⁵ which lays out the definitions involved within confidentiality and the service provider's obligations.

⁵

[http://www.hse.ie/eng/services/Publications/pp/ict/Service Provider Confidentiality Agreement.pdf](http://www.hse.ie/eng/services/Publications/pp/ict/Service_Provider_Confidentiality_Agreement.pdf)



6 Consent

Consent will involve the consideration of implications of certain decisions and actions. Informed consent means there is an understanding of the nature of what is being consented to and its implications. Where cognitive ability or ill health impairs that capacity, then an advocate (e.g. a family member or healthcare practitioner) is sought with respect to consent. Appropriate timing for a conversation on consent with a participant can make or break a creative encounter. As an artist you do not want to negate the reason you are there.

6.1 Mental health

6.1.1 Artists' perspective

Consent to participate within an acute unit; a day service or community group may differ to a degree. The artist has a responsibility to inform someone of

what an art workshop will involve before they choose to participate. An artist can explain the various types of workshop: process-led workshop where an exploration leads you to simply see what happens; a collaborative conversation on a project between participants and artist where the direction is negotiated; an artist led participatory project with a collaborative and specific artistic outcome; or a participatory project where the outcome is an artist's response to the conversation. Having a strong arts practice and understanding how you work will support you in determining your intent. In a collaborative work as an artist you will need to decide where do you draw the line of your input working alongside a participant. If a participant requires an artist led project, you can adapt to what is needed so long as your intention is open and clear.

Documentation of any project or programme is part of the collection of evidence of what is involved as a professional artist practising in participatory arts. This may be for documentation of an artist practice, a funding requirement, or for promotion of work within the health services, whatever the reason consent by the participants will be required whether this is verbal or in a written form. Artists spoke of their concern that consent can be given and later be withdrawn by the participant and there are complications from this, while the artist fully understands the rights of the participant need to be safeguarded. This instance has led in one programme to develop a detailed consent form with a second phase of consent, which includes permission to contact a patient when they have left the service if needed in relation to exhibiting work. This consent form was negotiated in consultation with appropriate healthcare professionals.

Seeking consent is part of our practice but as artists we need to understand that someone giving consent can be an uncomfortable decision for them. Consent should not be presumed and time should be allocated to the participant for consideration. In our work as artists we need to work with respect and responsibility towards the participants we encounter. They own their experience and the work created, for them it may not be important for it to be shared as part of the wider project, and if this is the case we need to respect this decision.

6.1.2 Healthcare professionals' view

A psychiatrist with experience of working as a scientist in an interdisciplinary, collaborative work with an artist spoke of consultations in their project. Consultations with families meant they were given all the circumstances and

implications of their stories being part of a curated show to be shared in exhibition in a public sphere. Leaving them with a full understanding of what this meant, families had time for consideration of what they wanted to remain confidential and what they wanted to share with others as part of this collection of work. The psychiatrist's view was that fully informed consent was the only way of working.

Within an acute hospital there are voluntary and involuntary patients in for treatment when they are unwell. Without creating any more stigma around someone with mental health issues, there is a need for artists understanding of this distinction: a voluntary patient in an acute hospital setting will consent or not to treatments; an involuntary patient would be in a different legal place and under the mental health act may be given treatment if it is in their best interest in terms of medical treatment. This distinction between voluntary and involuntary has no relationship to art and therefore has no implications in whether someone consents to be involved or not. One psychiatrist pointed out that we should not create more stigma by creating an issue around this area where there should not be one. Their fear was artists considering the division in this medical definition, that one could create more stigma within an area that already has to campaign for a true understanding of the illness.

An artist needs to be respectful and has a responsibility to look at a participant's capacity to consent when it comes to documentation and curation of work made. Capacity can be established with consultation with healthcare professionals. If work was being developed for dissemination in a public forum and an artist has any doubt to the capacity of consent in consultation with healthcare professional a family could be consulted if appropriate.

New legislation is being drawn up which will cover all healthcare settings in all scenarios looking at the capacity to consent from someone who's judgement may be impaired. The bill being reformed to comply with the UN Convention on the Rights of Persons with Disabilities led to the publication of the Assisted Decision-Making (Capacity) Bill 2013 ⁶. Historically, lack of mental capacity has resulted in the removal of legal capacity and this has disproportionately affected people with disabilities. In this bill it is primarily people with cognitive disabilities (intellectual disabilities, psycho-social disabilities, neurological disabilities and forms of dementia) that are required to undergo an assessment of mental capacity in the first place. The bill has been reviewed and commented on nationwide by Healthcare professionals. It is hoped that the

⁶ <http://www.oireachtas.ie/documents/bills28/bills/2013/8313/b8313d.pdf>

implementation of this bill will offer real hope for the empowerment of thousands of individuals who require assistance making certain decisions at certain times. It places strong emphasis on the “will and preferences”⁷ of the individual and this increased recognition has been welcomed. Whether all of this will have an impact on arts and health will remain to be seen.

6.1.3 Arts Co-ordinators’ view

Informed consent can be seen as a ‘follow through’ to tease out the implications of certain decisions and actions so it might not necessarily involve a patient’s doctor or family member. It also means understanding the nature of what is being consented to and its implications, which are important in a health setting where we are working with vulnerable groups. Where cognitive ability or ill health impairs that capacity, then an advocate (e.g. a family member or healthcare practitioner) is sought with respect to consent.

Consent forms that artists are using in a co-ordinated programme are influenced by a medical base and in consultation with healthcare professionals. There will be a continual evolvement in these forms, which will be changed appropriately and regularly. There are also codes of practice put in place to deal with issues that arise in the correct manner. Artists need an awareness of boundaries with a participant i.e. not having inappropriate contact outside of the health setting, which should be discussed at the initiation of the artists work within this area.

An artist needs to meet a person on an equal level. You may be there to facilitate others to find their direction through the arts but an artist needs to work with common sense, morality and honesty in process. When you are working with someone who is vulnerable you are building up a trust in that encounter. Ownership will build up through a group and an artist can change the way of working in response to participants’ feedback.

⁷

[http://www.irishpsychiatry.ie/Libraries/External_Events_Documents/Response to Assisted Decision Making Capacity Bill Nov 2013.sflb.ashx](http://www.irishpsychiatry.ie/Libraries/External_Events_Documents/Response_to_Assisted_Decision_Making_Capacity_Bill_Nov_2013.sflb.ashx)

6.2 Alzheimer's

6.2.1 Artists' perspective

Consent should be informed. It can be a process over time when the artist builds up a relationship with a participant and there is a responsibility on the artist to ensure that there is an understanding in what is being consented to at all stages. This work may be capturing the moment and documenting this appropriately, which may require the consent to be given from the beginning of the process.

Artists shared a conversation on the responsibility of completing an outcome true to the interaction with a participant. This is why the clear intention of the work needs to be shared, so that there is no manipulation of the artwork intentionally or unintentionally.

Artists looked at involvement in participatory art from different perspectives. Sharing a conversation with the group we considered the question of 'Is it appropriate?' and people's right to the dignity of risk. Having an experience that you may dislike is as valid as an experience that you like when it comes to engaging and looking at art. Everyone has an entitlement to look at art and should be given the choice of their participation or not; though obviously this must be tempered with caution of appropriate content to prevent a risk of triggering anything upsetting to a participant. Open communication from the outset in an agenda and intention between parties continues to echo through every discussion.

6.2.2 Healthcare professionals' view:

"Consent is an ongoing process when people with dementia are involved. It is important to continuously ensure that the person is happy to be involved and that they understand the work being undertaken. Getting consent from a person with dementia to engage in an activity, particularly those that will be available publicly cannot be a tick box exercise. You need time to talk through

the issues and make sure the person understands what is involved, the purpose of the piece and how it will be used.”⁸

With the nature of the condition in the early stages you will be able to get verbal and written consent. Consent will be gained through a relationship that has been built up with the participant in question, understanding someone’s needs and health, building an appropriate approach of consent. Later stages of Alzheimer’s you would need to take an alternative approach identifying will and preference including use of visual cues such as using objects or pictures to help someone understand or observing physical response to conversation. While seeking as many opinions as possible including family input to gain consent. Consent is a process.

6.3 Oncology

6.3.1 Artists’ perspective

Working within Oncology may mean working in one of a selection of settings including a hospice, treatment day ward or long stay ward. An artist introducing the concept of opportunity to be involved in an arts project knows that there is an ‘opt in/opt out’ selection for anyone being offered the opportunity. The artist in their preparation of their project organises the aim, objectives and proposed outcome that can be clearly presented at the appropriate time of meeting someone who may become involved in the participatory art. Someone may be unwell physically but their mind is clear to make their own consent.

Participants may be involved intermittently due to how they are physically and mentally on any day. Consent can be given by a participant for their artwork to be shared in one instance but retract this at a later stage. This experience has been shared in artists in a number of instances and can cause difficulties.

⁸ Avril Easton. Project Leader - Dementia Friendly Communities. The Alzheimer Society of Ireland.

Concerns were raised in experiences where a family member had a veto on their loved one's consent, this raised a further question of 'Who has the final say?' the participant who created the work or the family member for his or her own reason who are overriding the consent? Can a family member veto consent; as in their opinion 'they were dying and it doesn't count?'

Consent being sought posthumously will bring a second phase of consent. Some artists have considered this and in one programme forms have been created with the support of healthcare professionals. This phase of consent is then sensitively and appropriately discussed with a family. The healthcare professional choosing a suitable time, with the necessary support structure in place for those involved. Having this structure between the artist, healthcare professional and participant's family member means everyone has a full understanding of what the consent means and why it is being sought.

The consent for documentation that is required in a project, to record the moment in its truth is part of the process. Although the question that was raised, "Who is the documentation for?" circles in an artist mind when they are documenting the work. The dissemination and publicity created of this documentation is how we are going to remember a project and needs to be approached with professionalism. For all involved an artist needs to represent the experiences encountered as it was and without bias in representing the work that promotes the artist's individual agenda.

6.3.2 Healthcare professionals' view

"Being involved in an arts programme should be seen as part of the service," said a consultant in clinical oncology. Consent can be given by the patient whether they are interested in being involved or not, without any issue. There was also the comment that the same principles of medical ethics could be applied to participatory art in an Arts and Health context.

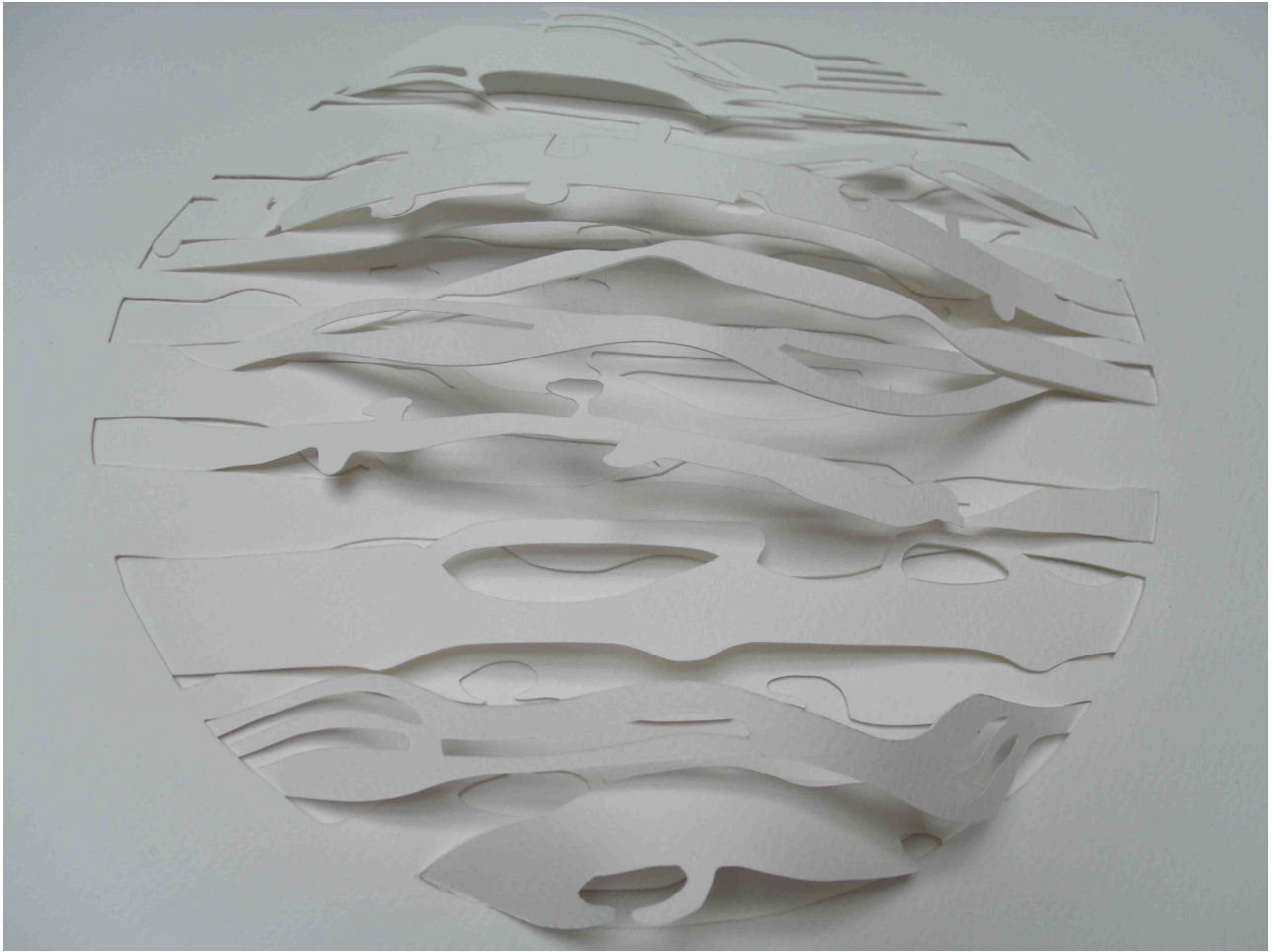
I contemplated medical ethics from an arts and health perspective to consider this opinion. Medical ethics is trying to do the right thing while achieving the best possible outcome for every patient. Principles and theories in medical ethics apply to just about every problem or situation. The principles address the issue of fairness, honesty, and respect for fellow human beings. Autonomy: People have the right to control what happens to their bodies; *participants consent is dependant on their interest in involvement*. Beneficence: All healthcare providers must strive to improve their patient's health, but what is good for one patient may not be good for another, so each situation should be

considered individually. Other values that might conflict with beneficence may need to be considered. *Participants are considered as the individual they are and how they can benefit from creative exploration.* Nonmaleficence: “First, do no harm”. You should also be aware of the doctrine of double effect, where a treatment intended for good unintentionally causes harm. This doctrine helps you make difficult decisions about whether actions with double effects can be undertaken. *Content of a project can be developed to challenge the participant, while carefully considering anything that would unintentionally cause harm in its making or curation.* Justice: You should be able to justify your actions in every situation. *If there is open communication from day one and clarity of intent throughout there will be no need to justify actions.* Informed consent is an overarching point in medical ethics; yet reaching informed consent can be difficult.

6.3.3 Arts Co-ordinators’ view

When art is for the participant, is there need for evidence? Documentation of participatory art has its place but when the need for evidence overtakes the importance of the participant’s involvement in exploring creativity, is there a need to review the approach? Appropriate timing for artist’s documentation is important that it does not break the connection in the artistic process between themselves and participants.

Healthcare professionals support is invaluable. The partnership that is created between staff and artists is vital for strength to form in arts and health. The healthcare professionals contribution and support creates a format that can be effective and without this in place it creates difficulty in progression.



7 Decision-making

For all individual and collaborative working methodologies in this context; there will be different decisions to be made. Decisions can be shared and considered by a selection of parties of interest in alternative ways. Each setting has its own structure and a freelance artist may experience the decisions being considered different to those artists working within a co ordinated programme, each integral in its own approach.

7.1 Mental health.

7.1.1 Artists' perspective

Decision-making comes into play from the initiation of an artist becoming involved in a project in an arts and health context. Artists working freelance or

within a co-ordinated programme for an organisation or institution need a liaison contact within that organisation This could be an Arts Co-ordinator, Clinical Nurse Manager, Occupational Therapist or other healthcare professional. Partners or parties of interest need to be identified so from the beginning there is a transparent negotiation between all involved for a clear understanding of intention on all sides. Having been in contact with artists from a variety of settings within arts and health spread geographically nationally, the structure of this 'clarity of intent' varies in its format and negotiation. This can include: considering agenda; motivation; aims and objectives; organisation; healthcare professionals input; funder support and expectation; partners voice and support.

Different strands within arts and health have a range of artistic vision, goals and outcomes. There is a diversity of art forms, contexts, partnerships and supported structures within the full range of arts and health practice.

An artist develops an aesthetic experience, developing work to enhance the hospital environment or work for social engagement. An artist develops a practice that will engage the staff and patients encouraging service improvement, through the wellbeing of staff and patient equally. An arts programme integrates into the culture and practice of healthcare settings, where artists place an emphasis on participant centred projects. An artist develops a collaborative practice developing conversation with participants leading to exploration of art and its potential. An artist works to encourage exploration of art, its media and technique while developing participants' knowledge and inspiring their artistic interests. The methodology of artists' participatory practice will influence decisions on how a project will compliment the participant needs.

Clarifying the method and intention will have led an artist to consider what they are doing – their motivation and agenda. A question being formed from sharing conversation with artists in their experiences and encounters, is 'What is Art?' Artists are experienced in giving explanations to the onlooker of art to 'what it is' and 'what makes art' in their view while developing a conversation of understanding, acceptance of this is then at the discretion of the viewer.

Artwork within a medical environment has a specific set of requirements and demands. Artist introduction of contemporary practice has a place in participatory arts but it needs to be appropriate for a health context. Contemporary arts practice has the freedom to raise interesting questions for a meeting point between art and medicine in a useful manner, artists intending to explore this direction will need to work sensitively. Within participatory art are we setting out to create work with an intended social

impact, transforming public policy? Is it what art can do? It is for an artist to question where they are on this scale between artists changing public opinion and participants' creative opportunity. Is it the aesthetical impact that participatory arts has? Based in a medical environment, bringing these questions into a public arena where the wider society needs to tackle them head on may not be the priority of the work. The question needs to be asked 'Who is the participatory art there for?' While having an opportunity to explore a cultural experience through the arts, the artist must be clear in their intentions and ask in this work whom is the beneficiary?

Developing work with participants that depicts someone's life needs to be approached with clear intentions of whether the audience has a window through this artwork in the form of a documentary or art. Otherwise what are the ethical implications of divergent interpretations? It's clear that ethics in Arts and Health is an area for further discussion. There is rarely space for artists to explore the ethics of our own practices or to reflect on the ethical dilemmas thrown up by the context we are working in.

A separate ethical conversation looked at artists' practice working in tandem extracting residue of value from participatory art to produce an artist's own work. Artists are naturally inspired by their encounters and this will happen as they work in healthcare settings. What is the expected value to people in a healthcare setting, what value is it to the artist? The question is then could this extension of participatory art be beneficial to both the artist and the participant.

7.1.2 Healthcare professionals' view

A Consultant Psychiatrist viewed arts involvement in the mental health service as a support in the development of a thoughtful and open culture interested in problems and lifestyles of people. Thinking outside the box can be helpful and a positive creative counter balance to the way nurses and doctors were taught in the past to look at the world and think in a scientific way that can have it limits. Artists often think differently to scientists and can provide a different perspective to help healthcare professionals respond to patients.

The mental health service has emerged from a difficult history; the relationship between the institution and the patient was forged within confinement and control. There are now strides being made to go beyond and

away from that. From this legacy changing the culture and challenging that history is about the involvement of creative people, but there may be tensions around the edges it may not be a smooth process. It may not fit neatly for a hospital that artists come into the setting looking for Arts to stimulate an active mind, but it's not always straightforward, it can be difficult.

Misunderstandings can take place so good open communication, understanding and a good personal relationship between staff and artists are important. Not everyone has the same approach, which is normal and we can value and celebrate this diversity of perspectives that are encountered, while working together on the areas of crossover. Mental health problems don't fit neatly into any singular framework. Education plays a crucial role in shaping our understanding of mental health issues and ways to respond to people experiencing distress.

A Community Mental Health Nurse involved in supporting a successful arts programme echoed this view that Art should be made a core part of the service. While endorsing the use of a project plan where the aims, objectives, schedule, costs and partners involved are all laid out so everyone has an understanding of the project in question.

One Psychiatrist noted that supervision has a place in participatory art. Who provides this is up for discussion, whether this takes place through an Arts co-ordinator or healthcare professional.

7.1.3 Arts Co-ordinators' view

Artists, staff and participants work collaboratively; this changes the dynamic of the group when all are involved and it equalises the relationship.

Collaborative work has artists working in ways that empower individuals and groups to co-produce work, from its inception to its reception. In decision-making there are a number of working methodologies in this context and the decision-making will be individual in each of the collaborations.

"In collaborative arts and health work, it's a complex negotiation of what we are doing together, how we are doing it etc. Having a clear intention helps and that this is clarified on all sides, but we also need to scope things out first to imagine what this could be. Consensus on all issues is not necessarily

preferable - it depends on so many factors including intention, interest, expertise etc.”⁹

7.2 Alzheimer’s

7.2.1 Artists’ perspective

Working in any health setting an artist should have an understanding of the policies that are in place working with people who are vulnerable. There is a code of practice in place for everyone’s safety. Artists shared how important it is to have open communication with someone whose cognition is impaired, informing how we work. Working with each person as the individual they are, just as we are, while developing an understanding of the experience lived by a participant. As artists we need to assess what we can offer and invest in the people we are working with.

In these settings an artist will need to look at how the work is to be centred on the participant. Working with the healthcare professional to consider the direction of the work, decisions can be made and intention can be made clear that supports and benefits those involved. As this process progresses the communication builds in strength, adapting to the needs of the participants.

Decisions are made on the completion of work in the curation. Artists discussed the impact of working within an environment creating work, which is then taken into a completely different environmental space for exhibition or dissemination. There is an importance of clear explanation of the intention, process and documentation. For example, if the process has been the emphasis it will need to have vivid representation. How a work is to be completed and presented may influence how a participant works and where possible these intentions should be shared from the beginning. Within this clear explanation the publicity and acknowledgement of the parties involved is agreed from the outset, is consulted throughout, and forms a part of the evaluation of the work on completion.

⁹ Niamh O’Connor. Artist/arts and health co coordinator.

7.2.2 Healthcare professionals' view

There was emphasis on the need for an artist to have an understanding in the area in a broad, meaningful and honest way. It was also highlighted that an artist needs to be open to what they can offer, what they are willing to explore and what they are willing to learn, not to be set in a way of working as there would be a need for adaptability alongside open communication for all parties.

Someone with Alzheimer's, like any other ailment, should not be prevented from a full quality of life. Another co-ordinator commented that opportunities to work in the moment and create something precious could mean a "Human's flourishing".

7.2.3 Arts Co-ordinators' view

Within a co-ordinated programme an artist's practice can be nurtured which will in turn support the strength of an arts programme. An artist working freelance within Arts and Health will have creative freedom, and an artist working in a co-ordinated programme will have the structure of support, procedures and policy, while also having creative freedom. For any programme working within the community there may need to be a collective responsibility to develop a policy and code of practice. Artists need to consult with the guidelines that are already in place: 'Solo practitioner code of practice for working with children and young people' by the Arts Council; ¹⁰ 'Participatory Arts Practice in Healthcare Contexts; Guidelines for Good Practice' by Waterford Healing Arts Trust and the Health Service Executive South (Cork) Arts + Health Programme. ¹¹

¹⁰ <http://www.artsandhealth.ie/wp-content/uploads/2011/08/AC-Solo-Practitioner-Guidelines.pdf>

¹¹ [http://www.waterfordhealingarts.com/userfiles/file/Participatory%20Arts%20in%20Health%20Guidelines%2009\(1\).pdf](http://www.waterfordhealingarts.com/userfiles/file/Participatory%20Arts%20in%20Health%20Guidelines%2009(1).pdf)

7.3 Oncology

7.3.1 Artists' perspective

Building an understanding of each other's backgrounds is important. There will be different language in a conversation between an artist, healthcare professional or partner coming from different fields. Learning what each other means in this communication will bring an understanding of each other's interest and in the development of arts and health. There is a space for crossover in the areas where there are similar points of view, along with the areas where there is a difference of opinion. The relationship will be able to build on the crossovers that are present.

Artists expressed interest in building links with healthcare professionals to support a project, understanding that the input and involvement of a staff member could make or break a project. Artists are aware that the healthcare sector are under extreme demands within their field and healthcare staff support arts and health as much as they can within their time constraints.

Within education of medical staff now there is an introduction to arts and aesthetics in the human condition and healthcare settings. Here students begin to develop articulacy on aesthetic experience, and how to work with both aesthetic and biomedical cultures. Understanding the importance, even if it is understated, the role of arts in health in the narrative of medicine and healthcare will give a new generation a new view of art's place. The involvement of this education can only be of benefit to the healthcare professional working alongside artists and those involved in seeing arts and health continue to develop.

A point of discussion that arose between artists was on the unwritten work that is involved in arts practice. Proposing projects and the paperwork that is involved can at times lend to a large amount of preparatory work before sitting down with participants to create a project concept. While in some situations this research and development time is recognised there are many instances where it is not. This linked to a discussion on artists working voluntarily due to budget restrictions and priorities within a health setting versus those artists contently working voluntarily as the work feeds into their studio practice.

7.3.2 Healthcare professionals' view

In terms of negotiation of an artist working within a healthcare setting, one Consultant in Clinical Oncology commented that there are medical limits and art can attend to human beings, through its medium we can encounter patients. An artist in their view should be authentic and have clear motivation and intention. The Arts is the first step to open creativity.

A Haematology nurse working with artists attached to the different teams across the hospital commented that the artist works independently as part of the package of what happens when someone is in the hospital. Consultants were consulted about artists working on the ward and their only point raised was awareness of infection control.

A number of healthcare professionals consulted touched on the arts and science integration. Arts and science in older days has been integrated and one healthcare professional viewed this split as artificial, questioning the future of Arts and Health and its direction and emphasis. They see that the institution needs to be part of big thinking, academia committing to Art, which can navigate and encourage interdisciplinary work. Another healthcare professional interested in fostering the debate of medicine's limits and how arts can throw a light on it sees Art as making a creative space to see what comes, that there is no need for 'data'. They were concerned that there is not a trap of falling into measuring worth and views a field of Medicine that can be infused and elaborated on by the humanities.

"Medicine is only partially fulfilled through technical skills, factual knowledge and moral reasoning. Good care centres on an authentic and empathic human interface. The arts are a repository of knowledge on this interface and, for this reason, are central to medicine." ¹²

7.3.3 Arts Co-ordinators' view

Open Communication from the outset is important. Understanding a different sector's language. You have to be open to understanding to what a different agency means in their terminology and sharing of its meanings, identifying areas where there is a link and being content with that. An artist is not trying to convert, they are trying to understand the other

¹² Dr Sam Guglani. Consultant Oncologist, Cheltenham
Curator & Director, Medicine Unboxed

agencies' language and acknowledge areas of crossover and areas of individual interest, working in parallel together. There is a flow in working with a number of stakeholders, it is just a case of finding it.

A doctor's view was once heard to say "Artists help healthcare professionals tolerate ambiguity."

8 Participatory Art

8.1 Reflection

In contemplating this project, I understood that a period of reflection on my practice would have an important place. To do this I carried out an eight-week participatory art project within an acute hospital unit within a Mental Healthcare setting. Alongside this period of reflection I explored a series of case studies looking at projects within different contexts, using different methodologies.

Aim of the project

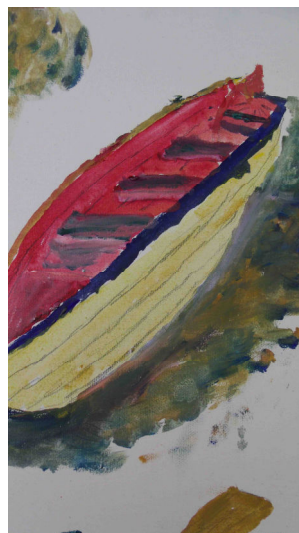
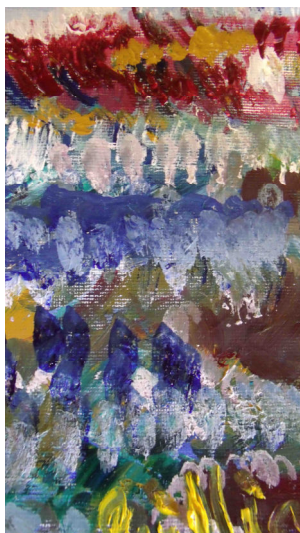
- Consider each step of the process of a participatory project

Objectives of the project

- Consultation with relevant healthcare professionals to clarify the intention and purpose of the short project
- Consider my approach in gaining consent as needed for documentation and curation purposes
- Negotiate collaborative conversation with participants
- Artistic outcome – create a series of artworks for hospital environment

Methodology

- Project concept introduced: 'Celebration of culture in Ireland'
- Facilitated participants' creative exploration, which evolved into a collaborative conversation between participants and artist



Due to the nature of this setting the participants involved would be continually changing. Collaborative art being created gave an opportunity for participants to explore what it meant for the aim of the work to be a collaborative outcome. This led to a fluid conversation from one participant's creative mark leading to another being inspired. Conversations took place with one participant who questioned how appropriate the depth of personal content to share in a collaborative project was, as they sat to write their response through poetry. We discussed how they could choose what they were comfortable sharing, while acknowledging the exhibit's audience. During the project another participant created a piece of work that may be viewed as dark but was their portrayal of the concept. This led me to question the curation of artwork within a healthcare environment and its effects on the audience.

Healthcare staff were consulted in relation to consent forms, which were given for participants to consider before any documentation photos were taken. Participants generally chose to consent and were pleased to view the images, while a few participants declined to be part of documentation of the project.

Reflective considerations

- Appropriate timing is needed to discuss consent
- The role of consent in collaborative art

Artistic outcome

- Collaborative artwork created was exhibited in the hospital space

Personal evaluation of this project gave me space to consider details of my practice that I can develop. Following reflection on my journalling and review of the project, I gave feedback to an Arts Co-ordinator connected to the setting. Following this, the design and implementation of appropriate policy has been agreed in principle, discussing areas such as: identifying relevant persons of contact; procedures in place for issues arising; exhibition policy; health and safety implications; allocated funds. Dates are being agreed during Autumn 2014 for meetings for further discussion.

8.2 Project's impact

During the later stages of this overall research project I undertook a participatory art project, which was informed by reflection on this research. This project took place in an Oncology day unit where there is treatment for outpatients.

This project was piloting participatory arts in a space that does not have a current participatory arts programme. The project's initiation was planned with the support of the hospital's Arts Co-ordinator and Clinical Nurse Manager of the unit. The participant's input was not possible in the planning in this instance due to the rotation of treatment.

Aim of the project:

- Introduce participatory art in a considered approach

Objectives of the project:

- Communicate openly with healthcare professionals whom I have contact with in order to create an understanding of participatory art
- Approach consent for documentation without negation of the arts process

Methodology:

- Facilitate participants' exploration of art within the restrictions of a treatment space
- Explore collaborative conversation and its direction



In this space there were considerations to be taken for patients undertaking treatment physically restricting their mobility. Practically I needed to be conscious in working around the staff's need to attend to participants' treatment. Healthcare staff supported the project and they encouraged the idea of participating to patients in their care.

Within this setting I implemented two methods – some patients chose to explore art techniques and develop their skills through resources provided, while others shared in a collaboration of conversation based on their ‘place of escape.’ This inspired an artist’s response being created in the moments of quietness of participation. Different methodologies are employed by artists in a variety of situations and the latter method here was a new approach to my practice.

Reflective considerations

- The artist’s role in collaborative art and an artist’s place in artistic response

Artistic outcome

- Individual artworks kept by the participants
- Artist’s responsive artwork from collaborative conversation between a number of participants and artist donated to the day unit

Evaluation outcome

- Healthcare professionals and participants saw benefits of the opportunity of having the choice of participatory art
- Provision of participatory art within a series of wards together would allow for participants’ involvement as requested during treatment

9 Conclusion

Having the time to consider Confidentiality, Consent and Decision Making in Arts and Health Participatory Art Practice quickly brought me to the realisation of the enormity of the area, due to the variables involved. In the completion of this research, in my view this is an area that needs further discussion as ultimately I have more questions than answers. At the beginning of this work I was contemplating the tensions that arise within this area but I now I realise that with open conversation any issues that arise can be worked through.

Confidentiality requires an artist's respect of participants following best practice guidelines. Responsibility lies with a professional artist working with vulnerable people within a health setting and part of this is adhering to contract terms and guidelines in place. Consent is not just one phase of ticked boxes; it is a process where participants have an option to opt in or out at any stage. This process is at its best when there is an open understanding of what is involved, making consent informed. When capacity of consent is in question, there is need for further conversation with the support of the appropriate parties. Decision-making will be made by every stakeholder in an arts and health project, where there will be a crossover of understanding in purpose and intention. An artist needs to clarify their intentions and methodologies in this process through open communication from the initial point.

Points of further discussion

"Who is it for?" may be an unresolved point for further discussion. Artists need to be asking themselves this while working alongside parties contemplating the intention of an arts project. How a participatory arts project is documented is how it will be remembered. Open communication between parties involved will determine the clear acknowledgement and intention of a project, so that there is no manipulation intentionally or unintentionally. Is the participatory project for the participant, the organisation, funder or artist? And "Who holds the power in participatory and collaborative arts?"

"What is Art?" this is undoubtedly a question that leads to an in-depth conversation in the arts and would be I believe a point for

future discussion within arts and health participatory arts practice. The complexity of artist methodologies will give a selection of directions. Who you ask this question of would also affect the answer, influenced by the intention, purpose and benefit that they see in arts and health.

Ethics and art is an area that needs further discussion, which will lead to many more questions. Some of which may include: how do we navigate ethics when working in partnership with several agencies with different needs, interests and agendas; how do we gather stories from vulnerable people, shape material and create art works in an ethical way; where is the artist's role in participatory art?

Another important question is who has the final say in terms of consent. Who decides whether the family have a veto or not, in the circumstances where a participant who creates artwork which they wish to be part of an exhibit? This question will vary on a case-to-case basis as 'capacity' may come in to question. Families may have their legitimate reason to speak up for a loved one's work on exhibit in a public forum. Further discussion on this area may lead to some clarity of answer including looking at whether an organisation/institute has the right to a say or censor the participants work on exhibit.

Arts and health professionals working together will lead great benefits for participatory art. Arts and sciences integration may be another area for discussion for artists, academics and organisations interested in the development of interdisciplinary work, while the collaborative work in place evolves. In undertaking this study I was aware that developments in my professional practice would be part of the integrated work. It has been a privilege to be a part of a dialogue sharing with artists, healthcare professionals and arts and health co-ordinators and their perspectives on this matter, all people who aim to have best practice in the forefront of their practices. In addressing this area I hope to encourage discussion between arts and health professionals whose focus is bringing together skills and priorities in healthcare settings. In presenting this work to Arts and Health Co-ordinators Ireland I hope to highlight artists' perspective and raise points for further discussion which could in turn benefit arts and health participatory arts practice.



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The staff and participants of Cork University Hospital Oncology Unit

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Healthcare professionals both in Ireland and the UK.

Arts and Health Co-ordinators

11 Bibliography

<http://medicineunboxed.jux.com/>

http://www.crawfordartgallery.ie/Beyond%20Diagnosis_medium%20res.pdf

<http://photoworks.org.uk/dialogues-perspectives-collaboration-focus/>

<http://vitalsigns.artscouncil.ie/>

http://www.crawfordartgallery.ie/Beyond%20Diagnosis_medium%20res.pdf

<http://www.helium.ie/programmes/professional-development/professional-development-reflect-lab/>

<http://www.artsandhealth.ie/case-studies/the-magician-and-the-swallows-tale/>

<http://www.artsandhealth.ie/case-studies/care/>

<http://www.3ts.ie/wp-content/uploads/2012/09/Lived-Lives-Overview-July-12.pdf>

<http://www.mariebrett.ie/egress.html>

<http://www.artsandhealth.ie/case-studies/cut-throat/>

<http://www.artscare.co.uk>

<http://www.artsandhealth.ie/perspectives/a-marriage-of-apparent-opposites-the-arts-in-medical-education/>

[http://www.academia.edu/4019730/Hell is Other People Ethics Aesthetics and Participatory Art](http://www.academia.edu/4019730/Hell_is_Other_People_Ethics_Aesthetics_and_Participatory_Art)

<http://collective-encounters.org.uk/wp-content/uploads/2014/01/Ethical-Practice-in-Participatory-Arts.pdf>

<http://collective-encounters.org.uk/wp-content/uploads/2011/11/Evaluation-and-Ethics-Nadine-Arendsen.pdf>

12 Appendix

12.1 Perspectives: Points of Discussion

	<i>Perspectives</i>	<i>Confidentiality</i>	<i>Consent</i>	<i>Decision Making</i>
<i>Mental Health</i>				
	<i>Artists</i>	Group boundaries Curation and identity Family/institutional influence	Informed consent Withdrawal of consent Respect	Clarity of Intent What is Art?
	<i>Healthcare Professionals</i>	Artist responsibility in curation	Informed consent Assisted Decision-Making (Capacity)	Arts counter balance Clear communication
	<i>Arts Co-ordinators</i>	Stigma	Consent forms	Collaborative Art Ethics in Art
<i>Alzheimer's</i>				
	<i>Artists</i>	Dignity	Clarity of Intent Dignity of risk	Participant centred Clarity
	<i>Healthcare Professionals</i>	Disclosure of Diagnosis	Process of consent	Understanding Opportunity to flourish
	<i>Arts Co-ordinators</i>			Freelance and co-ordinated Guidelines
<i>Oncology</i>				
	<i>Artists</i>	Contract Safe space	Opt in/Opt out Who has final say? Documentation	Language and Communication Education in medicine and arts
	<i>Healthcare Professionals</i>	Contract Guidelines	Medical ethics in arts and health	Arts and Science
	<i>Arts Co-ordinators</i>		Documentation	Language Areas of crossover

12.2 Artists' Recommendations

For artists by artists:

Working in arts and health participatory art there needs to be:

Clear Communication with each party involved

Planning; Objectives; Goals; Negotiation; Policy

Clarify your Intention

What you are bringing, delivering and taking

Methodology

Distinguish your method through your 'artist' brain.

Evaluation

How will this project be evaluated? According to what goals and model?
E.g. Medical; Experiential; Qualitative

Identify a "champion" within the organisation.

A staff member's expertise, support and understanding of what you are doing is invaluable

Continual professional development

Evolve, be empowered through peer support and networking

Don't make assumptions of what a person is able to do / or how they can participate

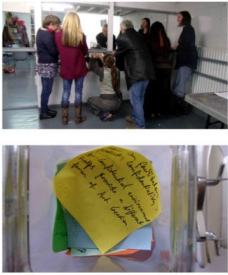
Listen and take time with the participant



12.3 Table of Images

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5	Peer dialogue workshop June 2014 Artists response exhibited at Peer dialogue September 2104 Peer Dialogue workshop August 2014
9	Artist's response to projects study of Confidentiality
15	Artist's response to projects study of Consent
23	Artist's response to projects study of Decision-Making
32	WCMHS Participatory Art WCMHS Participatory Art Participatory Art on exhibit in hospital space
34	Artist's response in participatory art. CUH. Participatory Art Cork University Hospital Collaborative conversation in CUH.
38	WCMHS. Participatory Art on exhibit Artist response to project on exhibit in CUH. Peer dialogue workshops conversation
41	August 2014 Peer dialogue workshop June 2014 Peer dialogue workshop June 2014 Peer dialogue workshop

12.4 AHCI presentation



Confidentiality,
Consent and
Decision Making in
Arts and Health
Participatory Art
Practice

1

**Presentation
Content**



Introduction

Methodology


Confidentiality,
Consent &
Decision Making

Participatory art

Conclusion

2



Introduction

Diversity of arts participatory
practice

Current Guidelines

Artists practice perspective

Conversation

3

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**Considerations
in Arts and Health**

Specifically within

Mental Health

Alzheimer's

Oncology



Confidentiality

Consent

Decision Making

5

Participatory Art

Reflection

Implementation of
developing practice

Piloted space

Collaborative practice



Healthcare Professionals
support



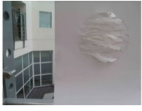

6

Recommendations

- Clear communication
- Clarity
- 'Artist brain'
- Evaluation
- Healthcare staff support
- Don't assume
- Continual Professional
development
- Listen

7



Conclusion

Responsibility of artist
Process of Consent
Purpose and Intention



Points for further discussion

Who is it for?
What is art?
Ethics in participatory art
Who has the final say?
Arts and Science

8

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