Ethics in human research: enriching understandings of participatory research.

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Abstract

This paper will argue that the process of applying for ethics approval in the social sciences provides an opportunity for deeper development and stronger research in art and design. The focus will be upon the relationships between the researchers and their participants. As such the paper will address the conference sub-theme of 'Identities/ Subjectivities'. In so doing the following questions will be explored and indirectly addressed to the audience: Who are your research participants? Who are *you* in your current research project? What are the relationships between you and your participants? These three questions will provide the structure for the paper, which will engage with the current ethics application and feedback form used by ethics' committees at the University of South Australia. An interpretative methodology will be used to critique research relationships in the processes of identification and subject formulation. A hypothetical example will be used to illustrate research relationships and ethical decisions which relate to art and design.

Keywords: ethics, relationships, identity, participants, art, design, race, gender.

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Relationships and research

Meaningful relationships, relationships built on mutual trust are one of the most precious things about humankind. They bear the fruits of friendship and love. We know this. But we also know that they are hard work. So too is the research process and it is useful to keep the metaphor of a solid and trusting personal relationship in mind whilst following the thread of this paper. The argument of the paper is that the process of obtaining ethics approval for research which involves human beings, is one that contributes to and deepens the research project. As a member of the Divisional Arts, Education and Social Sciences Human Ethics Committee (DHREC) at the University of South Australia, I am of the opinion that researchers in the fields of art and design shy away from engaging in participatory research because there is a myth that obtaining ethics approval is very difficult *or* because they may not realise that the research which they are already doing is indeed participatory human research which they should have received ethics approval for prior to commencing. Any type of research activity that engages with and involves human beings fits into the category of human research. And often in the case of art and design, there is not even a need to have additional participants (besides the artist) for ethical issues to be evident.

Artists and designers who are employed by the university and as a result are called upon to do research often get frustrated with the different categories of research and consultancy. It is frequently more than enough for them to try to justify that their most recent exhibition or design project qualifies as research and not consultancy without the additional hurdle of dealing with the fact that they have involved people in the process and should have obtained ethics approval for it. Here is the crux, most artists and designers are satisfied in the creative realm of their practice and furthermore they are great at making friends i.e. having relationships but they are not so good at administration, documentation – in short the bureaucratic side of matters. Art and even more recently design, have not been in the academy for long and by entering into the university both have had to conform to preconceived understandings of research. That is not the subject of this paper. But the subject of this paper argues

that the ethics application process can contribute to a clearer understanding of research requirements and research categories if artists and designers involve themselves in the process. Furthermore the ethics application can assist practise based artists and designers to work more confidently with text and create a balance between the artefact and its exegesis.

I cannot, for ethical reasons, use actual examples, so I have created a hypothetical but entirely probable example that artists and designers may be able to identify with. It is an example that applies to both HDR students and artists employed as university lecturers.

Example and explanation

An artist wants to create work that brings gender and race suppression into focus. This artist wishes to take in the first instance a series of photographs and in the second instance make a series of paintings. S/he knows that amongst her circle of friends it will be possible to persuade them to model, dress up and pose for this work and also for these friends to use their influence to get others to fill in gaps if for example s/he does not have enough participants of a particular gender or race as the work requires. S/he realises that this is an important component of her PhD by major studio project, or if the artist is a lecturer in a university art school, that this is work for an exhibition in a prominent gallery which s/he wishes to have categorised as research. In order for the PhD to be considered as examinable research and for the exhibited body of work to be considered as research, then within the academy there needs to be textual evidence in addition to visual manifestation. In the PhD scenario, the exegesis accompanies the art work, and with the lecturer's exhibition a 'scholarly' written catalogue is required. In addition to the artworks, the artist realises that it may be possible to develop some sort of questionnaire in order to have textual responses; however s/he is unsure how to proceed. While the idea is still at this conceptual stage, s/he talks about it with a research supervisor or a colleague in the art school and is advised to apply for ethics approval before going any further.

The example explained above raises a number of complex ethical issues that won't merely be solved by 'form filling', which the ethics approval process should *not* be seen as. However the process will provide the artist with the opportunity to share her/his project with experienced researchers where complexities can be considered and protective strategies put into place as well as providing the artist with access to legal and other professional advice. The process used by UniSA is *just one way* of implementing such strategies and will be referred to below as an example. The UniSA system is based upon an ethics proforma that provides specific headings and has set word limits, this is then reviewed by a panel in the one of the ethics committees and feedback based upon the application's headings is given as clearly as possible.

There are a number of things that the ethics application requires the researcher to do. (Refer to appendix 1 'Feedback on ethics application: request for amendment' upon which I have based the dot points below). The reason for working around the *feedback* is precisely because I want to emphasise how *improvements* can be made to the research. In a nutshell the researcher has to provide clarity on the following:

- o **A title**.

  The title of the work is written in two forms, the ethics committee requires a 'plain English' title that should tie in neatly with the aims and rationale.

- o **A checklist** which asks the researcher to nominate particular research methods that will be used (e.g. the type of questionnaire, interview, observational activity, experiment, focus group or action research). The checklist also asks the researcher to identify situations that will involve: indigenous people, children, risk of harm to researcher and/or participants, drug trials and illegal activities. The checklist also determines what sort of expertise will be needed to assess the ethics application, in other words, which committee it should go to.

The following points all deal with the methodology and process of the research in different ways.

- o **Aims and rationale**

  Here the aims of and reasons for the research need to be justified with a short literature review.

- o **Research questions**.

The research questions posed for the project have to clarify that no unethical demands are made in the process. This is also where the research methodology needs to be determined.

o **Data collection methods**.

Do the methods meet the aims?

o **Unethical demands or risks other than those referred to in the checklist above.**

Whilst the title and research question may not include obvious likelihood of harm or repercussions, there may be possibilities and the researcher needs to stipulate the preventative measures that will be put in place.

o **Selection criteria**.

These need to be fully justified in terms of the aims and issues of confidentiality must be covered.

o **Recruitment process**.

Evidence of non-coercion at this early stage of the process must be provided. Any dependent or un-even power relationships need to be clarified and procedures put in place to ensure equity.

o **Information provided to participants**.

The 'information sheet' is what participants receive before signing consent, it must be clear with no information withheld or disguised to mislead participants.

o **The consent form**.

The wording must be very clear, consent must be sought from all participants, all relevant details must be included.

o **Non-coercion**.

This is not only in recruitment and information at the early stages but also throughout the project. It must be clear that participants will not be persuaded to remain in the project for any reason and that they feel completely free to withdraw for any reason at any stage.

o **Confidentiality and security of data.**

The data and the outcomes of the research are often different. If names are to be withheld and images are to be disguised issues of confidentiality are crucial

and the secure storage of the data must be specified. If consent has been given for names and recognisable images to be used in the final exhibited or published outcomes, the original data still needs to be held secure so that it cannot be tampered with or used for other purposes.

In all of the above the emphasis is that the researcher must be absolutely transparent and unambiguous in the wording of the ethics application, the consent form and information forms, and the questionnaires.

Who are your research participants?

The above process demands that the researcher consider who s/he is involving in a number of different ways. For example how are the participants going to be identified and how are they going to be recruited? In the example above the participants come from a particular gay and lesbian community, which the researcher is familiar with. However, it is not ethical to approach friends and ask them to dress up or down for the purposes of an art work and one that is specifically geared towards highlighting issues of marginalisation, without careful scrutiny of the research objectives, consent forms and provisos to withdraw at any stage without recrimination and most importantly when all of these issues have been rigorously assessed by an ethics committee. In short, every participant (including the researcher) must be thoroughly informed of what will take place, what risks, if any, are involved and whether they are completely comfortable with the situation and proposed outcomes. A relationship of trust and respect has to be established in a professional manner.

Each one of the participants is an individual who may be superficially comfortable with posing for photographs and being the subject of paintings but when confronted with (perhaps) attaching a prosthesis that challenges issues of trans sexuality, or wearing apparel that expose racial stigmas, that person may experience feelings of pain that arise from residual or recent trauma. How then, are the participants going to be protected from discomfort? For instance, has the researcher made provision for follow up counselling in the event of e.g. PTSD (post traumatic stress disorder)? The participants may not really want their faces and bodies, recognisable or not, shown in a public gallery and reproduced in the media.   This is why the researcher needs to know who the research participants are. One by one, where do they come from, what

is their relevant history personal and otherwise? However this is not so simple because it is not ethical to ask deeply personal questions, therefore the researcher must be keenly sensitive to possible reactions and be thoroughly prepared for such eventualities.

There is always a context to research, the researcher brings her/his knowledges to the process and the respondents /participants bring theirs. Besides such previous or existing knowledge which if left unspoken can return to hinder the situation later, there is the specific context of place and time. Let's say that the art work as a type of performative portraiture is to take place in the studio of the artist in Adelaide Australia in 2008, which is to be videotaped during the process of making and then the 'finished' works are to be exhibited together with the screening of the footage at a local but estimable gallery in Adelaide in early 2009 with an agreement to tour South East Asia later in 2009. Producing this work, which challenges the suppression of racial, ethnic as well as LGBTQ (lesbian, gay, bisexual, transgender and queer) identities[1] may attract the attention of a centre right newspaper, which feeds a readership with facile sensationalism and consequently chooses to misrepresent the intention of the artist. This is only one possible consequence of the research. The artist/ researcher will be more prepared to respond to the media in a thoughtful manner if the research project is carefully planned in the initial stages and clear reciprocity of understanding is established between the research participants and the researcher. If the research takes place at another time in another country, one that does not countenance freedom of expression and specifically not in the vein of this research, the consequences will be different. However at all times and in all places, it is people that are being dealt with in research that involves human ethics and it is as individual people not merely as research participants that they should be understood. Whether or not they all belong to a similar gay and lesbian club, the unitary nature of identity is not a given. Roslyn Diprose questions 'the centrality of commonality on the basis of community', she writes that 'community lives on difference, on the touch of difference'. Drawing upon Emmanuel Lévinas' important work on ethics, she identifies where he stipulates that 'alterity' initiates 'sociality'.[2] Therefore whilst it may be easier to draw upon one type of group in order to gain access for the purpose of research, a group is never only a group.

The hypothetical example used for this paper would include two questionnaires in the ethics application, the participants who will also act as artists' models, will fill in the first questionnaire after the work has been made. There are a series of questions on the questionnaire that will ask the research participants demographic questions, personal questions and questions relating to their experience during the process of modelling for the paintings or posing for the photo shoots. Then there is a second, follow up questionnaire that they will complete once the work has been exhibited and received by the public. Therefore at this stage in the research process, that is prior to ethics approval and in the conceptualisation of the art project, the language of communication is entirely text based. The formulation and justification of the project is in the text based language of the dominant academic group and the only way to move beyond this stage and into the next stage of preferred visual as opposed to textual communication is to ensure that the text based communication that has taken place thus far is one that will perpetuate the integrity of the project. By using a language that is simple and accessible, participants can be reassured that their own subjectivities will not be tampered with beyond the point of their consent. There are information sheets and different types of consent forms (for use of images, taping and photographing etc) that the researcher will prepare for the project and the committee in conjunction with the questionnaires. Jonathan Crichton notes that the language used engages them in a dialogue 'in the Bahktinian sense' whereby the dialogue can take place beyond and without the physical presence.[3] Thus, the relationship is already being built. Even if there is some prior knowledge of who the participants are, the papers that they will receive before the language changes from text to image should be such that they are not coerced or falsely reassured but simply that they are being asked to take part in something that will hopefully contribute to a deeper understanding of the suffering of people whose identities have forced them for so long now, to live on the edge.

Who are *you* in your current research project?

Questioning oneself is never easy but as researchers, sometimes a chameleon like attitude takes place and the researcher takes on different identities in different research scenarios, which in this case is the production of art work in collaboration with other people. The researcher wants the research to be successful and that is part of the problem: 'success' and its devilish association with dominant practices. What needs to

be said is that because there are specific requirements in the research environment, but there is also the temptation to be and do what seems necessary at the time; i.e. to get the research output such as an exhibition or design piece done quickly to meet a deadline. Somehow, somewhere this is going to trip up the researcher and nowhere more obviously than in the ethics approval procedure. The researcher needs to deal with her own subjectivity in a scrupulously honest manner because the emotional and psychological well-being of respondents, participants and the artist/researcher herself are at stake. 'Exposure' and 'expression' are key elements in a Lévinasian approach to ethics, one where subjectivity and all its variations are made manifest in the visual and are synonymous with sincerity.[4]

Language as Elana Shohamy writes is a social and interactive activity and as Jonathan Crichton adds is 'a performance of the self'.[5] This performance is all the more manifest when the *visual* language of the artist is used in the example on race and gender exposure above. As a 'performance of the self' language is a reflection of the ideology of the self, it is what you offer to others. Foucault in some of his final lectures at the College de France says that it is not enough to 'know' yourself what is so much more important is to 'care' for oneself.[6] This paper has not selected an example where the artist her/himself is at direct risk of self harm (for example self mutilation) but this is another very valid type of example that could have been used in this paper. However, in the case of *any* exposure to danger be it physical or emotional to the artist's person and psyche or to the bodies and minds of participants, *if* there are participants, be they an audience that is participatory or not, they are people who will feel something. Therefore to care for oneself in the Foucaldian sense is also to care for others.

Conclusion

After completing the ethics application, making the necessary amendments and receiving final approval, the artist/designer is ready to commence the project. The artist/designer has at this stage made the shift and become a researcher without perhaps even realising it. In addition the tricky tension between text based or written research and visual/ artefact based research is on the way to being resolved because the ethics process has initiated the process. It is important to note that the process has only been initiated, the onus is upon the researcher to carry out the project with sensitivity and implement the protection strategies as the issues arise.

Rather than acting as a surveillance team the ethics committee and concomitant procedures are there to encourage sound research. Creative practitioners often have different and even conflicting ideas about methodology when compared with the more traditional academic disciplines. The ethics process is not there to make creative practitioners fit the mould either. However when there is confusion regarding the connection between research topic, aims and methodology – the ethics process helps to pin down the essentials by insisting on a careful scrutiny of the detailed mechanics of the project. Consequently the process assists the researcher in clarifying her or his own plans for the project and the rigour demanded by the ethics process could be a big step forward in attaining a successful research project.

In the process of applying for ethics clearance an awareness of the artist's place in a community of human beings is enriched. A sense of accountability on both an individual and a group level is enhanced and it is possible that the more artists and designers who go through the ethics process, the more socially responsible projects will also take place.

Endnotes

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[1] For a close reading of queer politics within the realm of white race privilege, see Damien Riggs, *Priscilla, (White) Queen of the Desert: Queer Rights, race privilege.* (New York: Peter Lang, 2006). Riggs asserts that it is necessary to look at 'queer and privilege' simultaneously ... in order to develop an ethical basis from which to engage in queer rights in the context of a postcolonising nation'. (2006, 15).

[2] Rosalyn Diprose, 'The hand that writes community in blood' in *Cultural Studies Review* 9 no 1. (2003): 36, 38. See also Emmanuel Lévinas, *Ethics and infinity / Emmanuel Lévinas ; conversations with Philippe Nemo* ; translated by Richard A. Cohen. (Pittsburgh : Duquesne University Press, 1985).

[3] Jonathan Crichton, 'Language in Research' paper presented at the *Autumn School of Research,* University of South Australia, April 2008.

[4] Richard Sugarman ' Emmanuel Levinas, the Ethics of Face to Face/ The Religious Turn' in Anna-Teresa Tymieniecka, *Phenomenology world wide: Foundations, expanding dynamics, life engagements.* (London: Kluwer Academic publishers, 2002), 420. . See also Lévinas' *Otherwise than Being: or Beyond Essence.* trans. Alphonso lingis (1974) (The Hague: Martinus Nijhoff, 1981), 153.

[5] Elana Shohamy, *Language and policy: hidden agendas and new approaches.* (London: Routledge, 2006), 5-8. And Crichton, 2008.

[6] Michel Foucault, *The hermeneutics of the subject: Lectures at the Collège de France 1981-9182.* Frédéric Gros, ed. And trans. Graham Burchell. (New York: Picador), 3.