# University of the Arts London
# Guidance for Research Ethics Approval

The University is committed to supporting good practice in research and scholarly activity; it regards it to be fundamental that research should be conducted in accordance with ethical principles. This document explains the University's procedures for dealing with applications for research ethics approval; it provides guidance on how to assess the ethical dimensions of your research; how to determine the ethical risks associated with a research project; and what steps you need to take to seek ethics approval for the project if that is needed.
This document is part of the University's framework for supporting good practice in research which includes the following related information:

- UAL Code of Practice on Research Ethics
- UAL Guidance for Research Ethics Approval [this document]
- Constitution and terms of reference for UAL Research Standards and Development Committee and Research Ethics Sub-Committee
- UAL Health and Safety Policy
- UAL Equality and Diversity Framework
- UAL Disciplinary Code

## 1. Code of Practice on Research Ethics

1.1 If you are not familiar with the University's Code of Practice on Research Ethics you should read it *before* reading this document. The guidance included in this document assumes you have read the UAL Code of Practice on Research Ethics.

## 2. Responsibilities for ethical approval, review and monitoring at UAL

2.1 The University's Research Standards and Development Committee (RSDC) is responsible for formulating and implementing research strategy across the University and for assuring the standards of the University's research projects and awards. Among its terms of reference is the task of setting and monitoring standards for research ethics. These obligations are fulfilled by the Research Ethics Sub-Committee (RES-C), a sub-committee of RSDC.

2.2 The purpose of RES-C is to consider and advise, as appropriate, on legal, moral and ethical issues relating to research. It is responsible for establishing the Code of Practice on Ethics to be promulgated within the University and for ensuring that research carried out at the University adheres to its Code of Practice on Research Ethics. It is responsible for reviewing codes of practice and guidance on ethics matters on a regular basis. It decides on applications for research ethics approval and advises the Research Standards and Development Committee, the Research Degrees Sub-Committee, College Research Committees, College Research Degrees Sub-Committees, and Partner College Research Degrees Sub-Committees as appropriate, on legal, moral and ethical issues relating to research. RES-C also monitors the devolved responsibility for the approval of research considered as

*minimal risk* by College Research Committees, College Research Degrees Sub-Committees and Partner College Research Degrees Sub-Committees. It oversees the Research Ethics training provided for research degree students at the University and reports annually to the Research Standards and Development Committee. The purpose of RES-C is set out in its terms of reference.

## 3. Procedure for considering the ethical dimensions of a research project - overview

3.1 All researchers engaging in research associated with the University should consider the ethical dimensions of their work. It is the responsibility of researchers to be familiar with, and conform to, the University's Code of Practice on Research Ethics.

3.2 If the research involves any of the following elements then the research is likely to have an ethical dimension for which *approval must be obtained*

- Involvement of other participants - actively or passively: including persons acting in a professional capacity, members of the public, children and others who are not able to give informed consent (refer to 4.6 below)
- Research collaboration with external parties
- The involvement of animals
- The use of human tissue (defined in 5.4 below)
- Potential adverse impacts on the environment
- Health and safety risks beyond those experienced in everyday life including to the researcher(s)

3.3 If any of the elements in 3.2 apply to the research an *application for research ethics approval* must be made. For research students this should be submitted to the College Research Degrees Sub-Committee in the first instance. For staff conducting research, application for approval should be made to the College Research Committee in the first instance.

3.4 Researchers applying for research ethics approval must apply using the University's research ethics approval form. This requires the researcher to supply information about the project and to make an assessment of the risk in relation to the guiding principles set out in the University's Code of Practice on Research Ethics. Risk is either minimal or more than minimal. Guidance on how to assess the risk is given by this document. When applying for ethics approval it is essential to enter a response for every item on the form so that Committees are able to make an informed decision promptly through provision of the full facts. It is not acceptable to leave entries blank.

3.5 In many cases, research ethics approval is sought because the proposal involves participants, in these cases additional material must be submitted with the ethics approval form, usually participant information material and participant consent forms. Guidance on informed consent is provided below in section 4 of this document.

3.6 College Research Committees and College Research Degrees Sub-Committees have delegated authority to approve research proposals which they assess as minimal risk. These decisions are monitored by the Research Ethics Sub-Committee. Applications which these committees judge to be more than minimal risk are referred to RES-C for consideration and are not approved by College committees. From time to time Colleges may also refer applications to RES-C where risk is difficult to assess (for example where some specialist expertise or advice is required).

3.7 It is important to understand that the judgement of the level of risk is distinct from the approval of research activity.

3.8 The ethical dimensions of a research project may change during the course of a project. It is important for the researcher to monitor developments for ethical implications and **to seek approval, or approval of changes** when changes affect ethical dimensions significantly. Examples are changes that affect the need to seek approval (3.2 above) or that affect the nature of participation (e.g. communities participating and/or what is appropriate participant information) or the category of risk (minimal to more than minimal or vice versa).

3.9 Failure to provide adequate information is by far the single most significant factor in delaying research ethics approval (see 3.4 and 3.5).

3.10 A failure to disclose information in a timely fashion to the relevant college research body or the Research Ethics Sub-Committee or the relevant Chair may constrain a researcher's ability to continue with the identified project and in the case of a student may inhibit his/her progression and qualification.

3.11 All researchers are expected to abide by the decision of the relevant college research body or Research Ethics Sub-Committee. Research projects may be monitored, and may be called in for review at any time by either the relevant college research body or the Research Ethics Sub- Committee.

## 4. Informed consent

4.1 The prior consent of a potential participant is essential in research involving participants. Such consent is called **informed consent**. For consent to be legally valid, there are three requirements:

- the potential participant must be competent, i.e. of adequate age and having the necessary mental capacity
- the consent must be voluntary, i.e. the potential participant must be free from inducement, coercion or undue influence
- adequate and appropriate information must have been given to the potential participant.

4.2 Informed consent exists to protect the subject, not the researcher. It is important to remember that the pursuit of knowledge is not a justification for ignoring the interests of those studied or asked to take part.

4.3 Informed consent in research is a dynamic, on-going process, not a one-off event, and may require renegotiation over time depending on the nature and timescale of the project and the use and dissemination of any data. It is an issue to which the researcher should return periodically both during the course of the research and after its completion. Researchers should, where appropriate, identify the possible need for renegotiation of consent, particularly where the research takes place over a lengthy timescale, where the nature or outcome of the research changes, or where data obtained is to be used in a way not covered by the original consent. In some of these cases it may be necessary to submit further documentation for approval to the Research Ethics Sub-Committee.

4.4 The quality of the consent obtained is critical to its validity (see 4.1). The onus is on the researcher to ensure that the consent is freely given and fully informed. The quality of the consent is affected by a number of factors, these being: the format of the record of consent, the competence and capacity of the subject/ participant to give consent, and the clarity of the information provided to the subject/ participant.

4.5 **Format of the record of consent** Wherever possible a signed consent form should be obtained. If written consent is not possible, oral consent can be given after the researcher or assistant has read out the details of the consent form and information sheet. This should preferably be witnessed by a second person and recorded with time and date stamp, either on video (preferable) or sound. When 'light touch' consent is appropriate the recording of consent must be consistent with the research design (e.g. where visitors to an exhibition are asked a few questions without supplying their name or address). Consistency is important, for example, if information is being collected *without* identifying data, obtaining the participant's signature would invalidate an agreement to preserve anonymity.

4.6 **Competence and capacity to give consent** There are a number of circumstances where the competence and/ or capacity of participants is absent or compromised. These circumstances typically fall within the following categories, however this list is not exhaustive and researchers should consider the issues of competence and capacity for all participant groups.

- **Children and young persons** Research involving children under 16 will require the informed consent of parents, carers or guardians. Young persons (i.e. between the ages of 16 – 18) are generally thought to be able to give informed consent but it might be appropriate to seek advice depending on the nature of the work. Courts of law presume competence from the age of 14. All researchers intending to work with children should endeavour to gain informed consent from the child participants in addition to the required consent of their parents or legal guardians. Regardless of these consents, it is the responsibility of the researcher to safeguard the rights of children participants.

- **Adults incompetent to consent to research** Where adult participants are not in a position to give informed consent the researcher should have regard to the Mental Capacity Act (2005) and specialist legal advice should be sought.

- **Other vulnerable groups** There are many factors that may affect the ability of participants to freely give informed consent, for example institutional groups (employees, prisoners, patients) may feel coerced into taking part in research by the consent of the institutional authority to carry out research within their domain. Researchers should, therefore, ensure that members of an institutionalised group understand that the institutional consent places them under no greater obligation to participate in the research.

- **Other factors which may affect voluntariness** Voluntariness can be called into question when other pressures may be an influence for example when a university teacher proposes to use students as participants in his research, or when researchers propose to pay participants more than their expenses and lost earnings.

In cases where **significant cultural differences may affect understandings about the nature of informed consent** the researcher should employ culturally appropriate methods to allow subjects to make decisions to participate or to withdraw from the research process.

4.7 Where the nature of the research is such that informing participants of some details before the work is carried out might render the results invalid, for example within aspects of the social and cognitive sciences such as perception, there must be appropriate explanations following the study. In these circumstances, justification for this course of action is required to be submitted for approval to the Research Ethics Sub-Committee. Researchers must provide convincing reasons why such research should proceed without the necessary informed consent. Researchers should not mislead participants if it is thought that prior permission will not be obtained.

4.8 **Clarity of the information provided** Consent forms and information sheets should be written in language which is appropriate for the participant. They should avoid using jargon, be as simple, accessible and appropriate as possible. Descriptions of the project should be written specifically to make sense from a participant point of view.

4.9 Participants should be given sufficient time to understand the information, to ask questions and to express any concerns that they may have.

4.10 An essential element of informed consent is telling participants clearly the following:

- the purpose of the research, expected duration, and procedures
- **what they are being asked to do**
- their right to decline to participate and to withdraw from the research once participation has begun

- the foreseeable consequences of declining or withdrawing
- reasonably foreseeable factors that may be expected to influence their willingness to participate such as potential risks, discomfort, or adverse effects
- any prospective research benefits
- limits of confidentiality
- incentives for participation and
- who to contact for questions about the research.

4.11 Participant information must contain *university* contact details for the researcher via a contact in Research Management and Administration at the University of the Arts London. Other contact details may also be appropriate for example at the site of the participation activity (e.g. within a museum), *personal* contact details such as home address or phone number of the researcher should not be given.

## 5. Clarification and definitions of terms

5.1 This section offers definitions to clarify terms which are often confusing or confused in research ethics applications. Terms introduced and clarified elsewhere in these guidelines (for example the meaning of informed consent) are not repeated here.

5.2 **Data protection** concerns the measures in place relating to the processing of information relating to individuals. Data protection is concerned with how data about individuals is obtained and kept (stored, held), and the uses or disclosure of such information. Personal data can only be collected and stored for the specific purposes declared at the time of collection. It cannot be used for purposes other than these nor can it be passed on to others for different purposes. Data collected should be relevant and sufficient for the purpose of its collection. There is an obligation on the person or organisation holding the data to make sure it is kept securely to assure its use only for the purposes for which it was obtained, by those authorised to use it; that it is not kept longer than necessary; and that it is not passed on to third parties. The Data Protection Act is the legislation which covers these matters.

5.3 **Privacy, confidentiality, and security** These terms are often not used accurately in research ethics approval applications. It is important to use the correct term for what is meant, the terms are not interchangeable. **Privacy and confidentiality** refer to an individual's rights about what information about them, or related to them, is made public. In obtaining information from individuals for research purposes it must be made plain to them what information will be made public, for example, whether what they disclose or tell will be anonymised or whether it will be attributed to, or associated with them as a recognisable person. Researchers should consider whether it is necessary to identify information with individuals or not, in some cases for example it may be critical to the research that the informant is identified, in others it may be possible to identify categories of informant which do not disclose individuals' identities, and in some other cases the identification of individuals may be entirely unnecessary. A respect for **privacy** is an acknowledgement that individuals have a right not to share certain information with others. Respecting an

agreement of **confidentiality** is to acknowledge that certain information may be disclosed to another (e.g. a researcher) for agreed purposes under agreed conditions of disclosure/non-disclosure to others. **Security**, in contrast, in the context of information, concerns the measures in place to ensure that only authorised persons or systems will have access to information. Thus, an application may make reference to the measures in place to ensure data is secure as part of provision for confidentiality.

5.4 **Human tissue** is defined as material that has come from a human body and consists of, or includes, human cells. Consent is the fundamental principle of the legislation regarding the use of human tissue: the Human Tissue Act 2004 lists the purposes for which consent is required.

## 6. Research ethics risk assessment

6.1 Researchers are expected to consider how to minimise the risks related to their research. This requires an assessment of risk and taking whatever steps are available to reduce the risks to which all participants in the research, including the researchers themselves, are exposed. This is sound research design.

6.2 **Minimal risk** is defined as an absence of any significant risk to anyone involved in the research, or any others affected by it directly or indirectly, that is reasonably foreseeable. This document is for guidance about ethical approval of research, thus the risks to be considered are those which might contravene the guiding principles or the researcher's obligations and responsibilities set out in the University's Code of Practice on Research Ethics.

6.3 **Ethics risk assessment** Researchers should always consider the ethical dimensions of their research. If the research involves any of the elements identified in section 3.2 of this document then the research is likely to have an ethical dimension for which *approval must be obtained* regardless of whether the risk is regarded as minimal or more than minimal. The risk assessment is documented by the applicant in the application for ethics approval (see 3.3 et seq. above for procedure).

6.4 Research which is likely to involve **more than minimal risk** requires an assessment which includes, but may not be confined to, consideration of whether any risks are posed to the researcher, to participants, to persons associated with them, or any other persons directly or indirectly involved. Such risks include, but are not limited to risks to:

- Health and safety of the participants and others
- Psychological welfare of the participants
- Security of the participants and others
- Reputation of the participants among their peers or in their communities
- Intellectual property rights of the participants.

6.5 Research which involves any of the following is likely to be regarded as potentially of **more than minimal risk** and will normally be referred on by College Research Committees and College Research Degrees Sub-Committees to RES-C:

- Research involving groups or individuals as identified in 4.6 above
- Research involving groups or individuals where the permission of a gatekeeper is normally required for initial access
- Research involving access to records of personal or confidential information concerning identifiable individuals
- Research involving the participation or observation of animals
- Research involving sensitive topics such as:
    - Sexual, political or illegal behaviour
    - Experience of violence; abuse; exploitation; racist or sexist behaviour
    - Mental health and/or treatment
    - Physical health and/or treatment
- Research involving interaction with individuals or communities where different cultural perceptions of ethics might result in misunderstandings
- Research involving deception, or which is conducted without participants' full and informed consent at the time the study is carried out
- Research that might induce psychological stress, anxiety or humiliation or cause more than minimal pain under any reasonably foreseeable circumstances
- Research involving intrusive interventions, including vigorous physical exercise, which participants would not normally experience or undergo in the course of their everyday life
- Research which might cause participants to reveal information which causes concern to them either at that time or later
- Research involving human tissue (note - such research may require specific approval by a research ethics committee approved by the Department of Health).

## 7. Examples of projects with minimal risk

7.1 To help researchers develop a sense of minimal risk and how to address it in research design the following typical scenarios are provided as illustrations.

**7.2 A study involving interviewing domain experts**

A researcher plans to interview eight artists/curators/designers for her thesis.
She offers a letter of introduction about the project, gains written informed consent for the interview from each interviewee, later checks the contents of the transcription with each interviewee, allows the interviewee to withdraw comments/ approve the interview record.
The interviews will be used as attributed statements within the thesis.
A recognised approach from oral history/ social sciences/ ethnography/ art and design criticism and history is part of the methodology.
The interviews will involve travel in the UK and abroad, the researcher has discussed her travel plans and personal safety with her supervisors.

**7.3 A study involving a large survey, followed up selectively for more in-depth information gathering**

A researcher is designing a project with a large scale survey to professionals in an industry, he plans to follow up the results from those who respond by conducting semi-structured interviews by phone/email/ or in person.

The survey will be sent by post/email to companies and known contacts.
The introductory letter explains the project, the survey and asks respondents if they will agree to be interviewed further or not. Respondents are asked whether the comments they report in the survey are their own or company policy and whether they are to be made anonymous or presented as pseudonyms in the thesis.

In the follow-up, interviewees receive further information about the results of the survey and how the semi-structured interview part of project will operate. Written informed consent for the interview is obtained and interviewees can check the transcript, withdraw comments, give approval, retain anonymity, or be named as interviewees and/or with reference to their company policy or position.
The interviews will be used as attributed or anonymous statements within the thesis.
The interviews will involve travel in the UK and abroad, the researcher has discussed his travel plans and personal safety with his supervisors.

### 7.4 A study which collects information via anonymous questionnaires

Two collaborating artist-researchers plan to conduct a survey of responses to their artwork in a public space or gallery. They gain the consent of the venue for this survey, which will be done by placing a questionnaire for responses in the space.

The questionnaire does not ask for names/addresses/emails/phone nos. but perhaps it does ask for age/gender/class/race of respondents. Filling in the questionnaire and leaving it in the gallery operates as 'consent' to take part. The questionnaire offers information about why the study is conducted and how it is going to be used. A separate notice and information sheet is also provided in the location stating why the survey is being conducted and how it will be used in a research project.

## 8 Case studies: projects with more than minimal risk

8.1 To help researchers to develop an awareness of the ethical dimensions of research generally and to assist in assessing the risk of a particular proposal this section of the guidelines offers some personal accounts of how more than minimal ethical risks were approached in a selection of projects.

### 8.2 Case Study 1: Working with vulnerable groups

My research project involved working with and photographing vulnerable trans-sexual groups. It raised serious issues on questions of

- Confidentiality/anonymity
- Informed consent
- Integrity of representation
- Reflexive methodology
- The need for constant, ongoing and responsive ethical review
- Personal relations built up through research process.

The participants were selected from this marginalised social group and sensitive personal data was collected. Through dissemination of the research findings participants risk exposure of their transsexual status and possible subsequent repercussions.

Ethical considerations informed the research throughout and were built into the formal structures of consent. I worked with my participants in a way that was highly responsive to their needs. They were consulted throughout the research process with respect to how they viewed the photographs of themselves that we produced. It is usual for the photographs presented in research outputs to be those that have been selected by the participants rather than by me. Participants have the final word in the selection and editing process – this applies to interview extracts as well as photographs. With regard to obtaining permission to use photographic portraits of a person, interview extracts and personal data I *obtain permission each and every time I wish to use material in a research output***.** If a participant is in any way hesitant about the material being used I will not use it.

I have worked in some of London's transgender/queer communities for over ten years. As a result I am quite well known – particularly in transsexual circles UK-wide – and trusted. I am aware that some of my current participants were happy to take part in my research because of this. While the way in which I work has advantages such as this – there are also disadvantages. For example, I can never be sure that I will be able to use (publish) a piece of work, but if there are objections no matter how significant or otherwise I consider them to be, I will then not use that material. However, the way that I look at this is that I am not just working on a research project – I am handling very sensitive areas of people's actual lives in a long term dialogue. While I may have a particular investment in specific research material being used/shown the people who are providing that material could be putting their lives at risk.

*Rigorous informed consent* was at the core of the research. Participants are given *details of the project, what it will require from them and my plans for dissemination before agreeing to take part in the research*. Participants are given the option of using a pseudonym and for their data/photographs to be kept confidential (using a code name in my records). Nobody other than myself has access to my research data and I do not pass information on to any other party. I only work with people who are able to give informed consent.

### 8.3 Case Study 2: Graffiti on the South Bank

This was a research proposal which sought to interview around 30 producers of legitimate graffiti at the South Bank Undercroft. Participants were to be interviewed about their opinions and ideas regarding activities and future possibilities for the Undercroft, and also where relevant, their own graffiti habits and key trends in graffiti practices. The key issues were

- Confidentiality
- Illegality of activities investigated.

Researchers working in pairs would take notes, and with consent, record the interviews. The findings would be fed as general observations and recommendations to the site managers, and would also be used to build experience for Research Council funding bids on graffiti.

The following risks to respondents were anticipated. Even though no personal details were to be recorded, *potential risk would be for participants to reveal illegal practices* such as inappropriate placement of graffiti and theft of spray cans (where participants were victims or had heard of other incidents); in theory, regular attendees could be traceable by police. However these were property crimes of a relatively minor nature and it was judged acceptable to give the participants an undertaking of confidentiality and that no identifying information would be passed to the site owners/managers (South Bank Centre) or the police.

It was felt *inappropriate to require a written consent form*, because respondents' identity would never be known and over-formality (in their sight) deterred them and would have impinged on the quality and value of the work and results. A light-touch combined oral information and consent procedure was developed, supplemented by a printed information sheet. *Signed consent forms would negate the anonymity*. The very fact of giving responses to the interview was deemed evidence of consent in these circumstances – but given the crime sensitivity, responses/judgements on participants' age, consent to be interviewed, consent to be recorded and consent for recording to be kept post-transcription were to be noted (without name, of course) as appropriate on a checklist by the second interviewer of the pair.

### 8.4 Case Study 3: Film making in Pakistan

Working within a film documentary practice and in an academic anthropological Ph.D. discourse, the ethics of imaging people heightened ethical issues about representation into intellectual properties over images, the crediting of images, the contextualising of images, the hierarchy of power relations embedded in film production, how viewers experience images and the authority of the camera/images as a visual language. The major ethical questions were

- The nature of 'informed consent'
- Its validity across cultures
- Managing and representing the agency of participants
- Equitable representation in post-production work and dissemination.

While I approached the ethical dimensions in the standard way - of thinking through what was involved and for whom, consent forms and information sheets, and so on - I was faced with a dilemma in the field, in that these processes were entirely impracticable and indeed open to misunderstanding. Filming in public spaces in Pakistan, people were unwilling to be drawn into what they perceived as an alarming 'officialdom' in an unstable political situation, in addition to which there were literacy problems in some cases. *Faced with these ethical problems throughout the documentary apparatus and production process I personally decided to use these as points of agency.* We would set up to film in a public space and started filming ourselves - this soon attracted a large and eager crowd. We asked people if they'd

like to join in, *explaining to them what was involved and what the filming would be used for. At that point they could make a decision as to whether to participate or not.*

I made this process clear in the filming and in my PhD in order to make my own position as film-maker clear, to pass this process onto the viewer and to start discussions with the people I was filming about the nature of interactions.

This has led me to believe that the ethics of the filming in the public space with a clear articulation of agency is not itself the substantial issue here. Almost all corners of the world are now saturated in image recording devices. The issue here is rather *how the ethics of an image are presented to the viewer, how one makes the film and the transparency of processes as an ethical position.* Ethical agency can be injected back into how these images are contextualised and consumed which I think is a critical issue. Thus ethics goes beyond *the ethics forms and must saturate the whole process of research.*

### 8.5 Case Study 4: Interviewing bike thieves

This was a research proposal which sought to interview about 10 thieves convicted of stealing bikes. The aim was to explore their perpetrator techniques and more generally to enable designers to 'think thief' in developing anti-theft designs for bike parking stands and wider parking facilities.
The thieves were to be identified with the assistance of a local probation department, and interviewed anonymously at their office. Ethical issues included the following

- Confidentiality and anonymity – this was guaranteed to the interviewees unless they revealed an extremely serious crime unsolved by or unknown to the police; or indicated that some future very serious harm might happen unless the interviewer took action. The interviewees were made aware of these exceptions in the information and consent forms. Apart from these extreme circumstances, there would be no supplying of any responses (anonymous or otherwise) to the collaborating judicial institutions, except what they saw in draft/published reports. In all cases the information would be unattributable, and often described in aggregate ('40% of thieves interviewed brought tools with them'); if individual cases or quotes were used, this would be handled with pseudonyms. Great care would be taken to avoid law enforcement/penal institutions identifying individuals.
- Free consent – the researchers would not seek actively to pressure offenders into agreeing to be interviewed (nor allow the 'supplying institution' to apply that pressure on their behalf), which could happen, for example by offering them improvement in their penal conditions. The researchers would avoid any hint of intervening in the criminal process by simply restricting interviews to offenders who had already been convicted and sentenced. They would not offer large monetary inducements (which could also harm the University's reputation in 'making crime pay') but would normally offer refreshments, expenses and a modest sum to recompense for time – say £10.

### 8.6 Case Study 5: Internet research

My research, for a practice-based PhD, involved engaging online presences in social networking sites under a pseudonym. It aimed to explore the ways in which identity is constructed online. There were key areas of ethical concern which proved extremely problematic and difficult to address because my proposed procedures were deemed to lack the required transparency. The following issues raised ethical questions:

- Researching online in social networking spaces under a pseudonym
- Using private emails in my thesis and thus copyright concerns
- Asking for informed consent in retrospect (after the emails had been exchanged) for using these emails in my research
- Working with a combination of both participants and collaborators.

These factors raised major questions about

- Transparency of the research process
- What constitutes 'deception' in the research process
- Processes of informed consent
- Confidentiality.

My research was such that it cannot be revealed as such in advance to those involved. One of the challenges marking the project was that I had hoped to develop a community of online presences into a community of offline friends. This plan, however, was abandoned, in part because it proved too difficult to get ethics approval. Instead, the research focuses on how the pseudonymous author 'Lucy' presented herself through her interactions with other profiles online. These other profiles are not really asked to 'do' anything in the research, beyond become the pseudonym's 'contact/friend', respond to the occasional email and engage in other typical modes of exchange in online social networking sites upon Lucy's prompting. I felt strongly that the response to my research *required a constructive approach to risk which both protected participants but also allowed the development of researchers committed to ethical research.* In practice this proved extremely difficult to achieve with a protracted negotiations on the ethical aspects of my research. The solutions which were put in place to enable the research to proceed in an ethically acceptable way were as follows:

- I agreed not to use private emails in the thesis
- RES-C agreed to waive informed consent from social network users, as there was no way to determine if consent was indeed informed and whether or not the user who initially gave their consent was the same user operating the user profile believed to have given consent.
- The Committee agreed to recognize online profiles as *representations* of identity. This is in contrast to perceiving them as actual people.

## 9 Design of participant information and consent form

A participant information sheet should allow a potential participant to decide whether or not they wish to take part in the research. It should provide clear information on the essential elements of the specific study: the topic being studied, the voluntary nature of involvement, what will happen during and after the study,

the participant's responsibilities, and the potential risks or inconvenience balanced against any possible benefits. The key to producing a clear set of information is to consider the participant's point of view. This means that first you need to briefly describe your project in a way that will make sense to the participant – this will answer the question 'why are you asking me to take part?'. Secondly, you need to explain clearly what you are asking a participant to do, this answers the question 'what are you asking me to do?'. Participant information is easy to read and understand if you write it as a series of questions which you answer in the text as simply as possible. Below we give some examples. These are just indications, you need to consider what is appropriate for the particular circumstances you are dealing with; using your own wording will demonstrate to research ethics committees that you have seriously considered the ethical dimensions of your research.

**9.1 Document heading**

We recommend the document is headed Participant Information and Consent Form.

**9.2 Research title**

One consistent title should appear on all the documents and be comprehensible to a lay person. Ask yourself: **Does this explain the study in simple English?**

**9.3 Invitation paragraph**

The invitation is to ask the potential participant to consider the study and then decide whether to take part. Both must be clearly explained. The following is an example:

*We would like to invite you to take part in our research. Before you decide we would like you to understand why the research is being carried out and what it would involve for you. We will go through the information sheet with you and answer any questions you have.*

**9.4 Purpose of the research**

Answer the question: **What is the purpose of the study?** Purpose is an important consideration for participants and we recommend that you present it clearly and succinctly and, if appropriate, in the brief context of other work in your field.

**9.5 Explain why you are inviting this participant to take part in your research**

Answer the question: **Why have I been invited?** You should explain briefly why and how the participant was chosen or recruited and how many others will be in the study.

**9.6 Explain that taking part is optional**

Answer the question: **Do I have to take part?** You should explain that taking part in the research is entirely voluntary. The following is an example:

*It is up to you to decide to join the research. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you*

*to sign a consent form. You are free to withdraw at any time, without giving a reason.*

**9.7 Explain what the participant will be asked to do**

Answer the two questions: **What will happen to me if I take part? What will I have to do?** To answer these questions, we suggest you try to "put yourself in the participant's shoes".

This section should include:

- how long the participant will be involved in the research;
- how long the research will last (if this is different);
- how often the participant will need to meet the researcher;
- how long these meetings will be and where they will take place;
- what exactly will happen e.g. access to personal information, a questionnaire, interview, discussion group, an activity, etc.

**Set down briefly and clearly what you will expect from your participants.**

Use the most appropriate format (e.g. tables, diagrams, photos, etc.) and not necessarily just words. The detail required will depend on the complexity of the study and who you are communicating with and the context in which you are approaching them.

You should inform the participant if your study will involve video/audio-taping or photography. Specific consent will be needed if you will publish material that identifies a participant.

**9.8 Consider each type of participation separately**

Many research projects involve more than one type of participation. For example you may be conducting a series of interviews with experts in a field (e.g. exhibition curators) and you may be running workshops (e.g. for visitors to exhibitions). These participant communities are different and their experience of engagement with the research will be different. It follows, therefore, that you need to provide different participant information and consent forms tailored for each type of participant.

**9.9 Expenses and payments**

You should explain if expenses (e.g. travel, meals, child-care, compensation for loss of earnings, etc.) are available and you should consider whether anything that you are intending to give as a 'thank-you' for participation, should be detailed in the information sheet. The arrangements for any other payment should be given.

**9.10 What are the possible disadvantages and risks of taking part?**

Any risks, discomfort or inconvenience to the participant should be outlined. You should consider insurance issues and explain any implications in the information you supply.

**9.11 What are the possible benefits of taking part?**

Explain these, but it is important not to exaggerate any possible benefits to the participants themselves. You ought to consider how you can give them access to your findings, if that is appropriate and they are interested.

**9.12 What happens when the research ends?**

Will there be any further contact with the participant? If so, explain what this will be (see 9.7 above – this is all part of the participant's experience of the research).

**9.13 Explain how a participant can withdraw from the study**

Answer the question: **What will happen if I don't want to carry on with the study?**

Explain what the subject can and can't expect if he or she withdraws. It may not be possible or desirable for data to be extracted and destroyed. The position on retention/destruction of data/artefacts on withdrawal must be made clear so that the participant can make an informed decision about whether or not to take part in the first place.

**9.14 What if there is a problem?**

You should inform participants how complaints will be handled and what redress may be available. A participant may want to contact the researcher or may wish to make a formal complaint. To accommodate either situation we recommend that the participant information includes information on how to contact the researcher (**use only institutional contact information**, not personal contact information such as personal telephone number or home address, e.g. give your university or college email address, postal address and telephone extension number) and also information on how to contact the institution's research office (or equivalent).

**9.15 Participant confidentiality**

Answer the question: **Will my taking part in this study be kept confidential?**

You should tell the participant how their confidentiality will be safeguarded during and after the study. You may wish to tell the participants how your procedures for handling, processing, storage and destruction of their data match the appropriate legislation.

The participant should be told: how their data will be collected; that it will be stored securely, giving the custodian and level of identifiability (e.g. whether it will be anonymised during storage, etc.); and what it will be used for. It must be made clear whether the data is to be retained for use in future studies and whether further Research Ethics approval will be sought; who will have access to identifiable data; how long it will be retained, and that it will be disposed of securely. Consider what your research requires – for example do not say data will be anonymised if it is critical to the research that data can be attributed to sources. Participants have the right to check the accuracy of data held about them and correct any errors.

**9.16 What will happen to the results of the research study?**

Participants often want to know the results of research they have taken part in. You should tell participants what will happen to the results of the research, whether and how it is intended to make public (e.g. publish, exhibit, broadcast) the results and how the results will be made available to participants. You should add that participants will not be identified in any report/publication unless they have given their consent.

**9.17 Make clear the institutional context of the research**

Answer the questions: **Who is organising and funding the research? Who has reviewed the study?** You should include the name of the College and of the University, and should identify any external sources of funding and should make reference to the University's procedures for Research Ethics scrutiny and approval.

**9.18 Keeping a record of participant consent**

Participants should be provided with their own copies of the participant information, which should be dated. It is easiest to maintain a record of participant consent if you append the consent items to the participant information document. The example of the form of the consent record given below will be suitable for many studies, and may be attached to, or be part of, the participant information sheet. The participant is consenting to everything described in the text of the information sheet.

For some studies a fuller, itemized, or hierarchical consent form may be needed to cover important issues, especially if additional elements are optional for the participant. These may include: consent to use of audio/video-taping, with possible use of verbatim quotation or use of photographs; and transfer of sensitive personal data to countries with less data protection.

The signatories to the consent should be those who are involved in the consent process, e.g. the participant and the researcher. An independent witness is not routinely required except in the case of consent by a participant who is blind, illiterate, etc.

**9.19 The consent form**

Once you have set out clearly the information to inform your participant, the consent record is fairly simple. We recommend that there are two copies: 1 for participant; 1 for researcher's file. Below we show typical content for this that you can customize to suit your particular project.

**CONSENT FORM**

Title of Project

Name of Researcher

Please initial box

1. I confirm that I have read and understand the information provided above dated.....(version.....) for the research study. I have had the opportunity to

consider the information, ask questions and I have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.

3. I agree to take part in the above study.

   Include:
   Name of Participant, Date, Participant Signature
   Name of Person taking consent (usually the researcher), Date, Signature.

   Finally, include the contact details of UAL's Research Management and Administration Research Students' section.

**9.20 Implicit Consent**

In some situations it may be appropriate to provide participant information without requiring a consent form which identifies the participant. An example might be if you are asking someone to answer a few questions anonymously at an exhibition. As long as you make it clear that participation is voluntary, agreeing to answer questions anonymously (verbally or by completing a questionnaire) can be regarded as implying consent to participate. However, the participant information provided should still meet the standards set out in the sections above.

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