



DIGIT-M-ED / Global Perspectives on Learning and Development with Digital Video-Editing Media: A Qualitative Inquiry in Everyday Lives of Marginalized Young People.

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Table of Contents

A. Introduction	5
B. Written and unwritten rules & ethical practices in research with youth in Germany, India, Brazil, Greece, and Russia	
B1. General attitudes towards research ethics in the various countries	7
B2. Who is responsible for the ethical review of research projects in the different countries?	8
B3. What kinds of data are considered “sensitive” in the different settings?	10
B4. What is the usual practice for a researcher or a research team to ensure that his or her/ their study is ethical?	11
B5. What kind of information does a consent form include?	12
B6. Is anonymity important in all local contexts? To which extent?	13
B7. How is visual data used in research and for knowledge dissemination purposes?	14
B8. Some particulars from the different settings	15
B9. Deontological underpinnings	15
C. Proposed guidelines and framework in cross-cultural/ trans-national youth research	
C1. Introduction	17
C2. What constitutes ethical interaction with human participants in qualitative field research?	18
C3. Ethical sensitivity in conducting social science research	25
D. Links and resources for further information	27
E. References	28
Appendix: Exemplary Informed Consent Form	29

A. Introduction

While social science research has become increasingly global in the past 15 years, the ethics and standards of practice in conducting cross-cultural, trans-national and/or comparative research remain vague. Since standards and rules are not delineated many questions arise. For example: Can an informed-consent form be used in cultures where people are skeptical towards written documents and may perceive researchers as representatives of the state which is often associated with top-down repressive policy-making and bureaucracy? Why should anonymity be respected if local people prefer to be referred to by their real names? What guidelines can be applied regarding the “proper” use of visual data for research and dissemination purposes when people, even within the same country, vary enormously with regard with what facility or difficulty they accept to be photographed or filmed?

Such questions cannot be answered definitively. Moreover, even if they could, who would be responsible for ensuring ethical research practices are applied and adhered to given the great variety in organizational structures, in the efficiency of control mechanisms and in beliefs about legality or authority around the globe? In order to compile a set of standards of practice in conducting social science research in different countries a study focusing on what practices, codes, standards and praxis exist in different settings would be essential. The Digit-M-Ed research staff exchange project *Global Perspectives on learning and development with Digital Video-Editing Media: A qualitative inquiry in everyday lives of marginalized young people* concerns the social, cultural, media-analytical and educational dimensions of digital media practices with a focus on the devices that are used for capturing, editing and circulating video data in Germany, Greece, Brazil, Russia and India. Within this framework we tried to map the similarities and differences in what is dubbed “ethical research practice” in the partner countries, and thus, take a first step into providing answers to the difficult questions outlined above concerning the ethics for cross-cultural and trans-national social-science research.

Generally speaking, the three major approaches to ethics are: the deontological approach, which states that we should identify and use a universal code in making ethical decisions, the ethical skepticism approaches which claim that ethical standards are not universal but are relative to one’s own particular culture and time, and emphasize the variety of values in different practical/ institutional etc. settings as well as the concerns of the involved participants, and the utilitarianism approach

which is rooted on the premise that decisions should be based on an examination and comparison of the costs and benefits that may arise from a study. As it becomes obvious, one approach is absolutist, the second is quite relativist, and the third takes a middle of the road approach stating that one needs to evaluate the costs and benefits and then make a decision. Without imposing judgment or our standards or preferences, we tried to develop understandings regarding the different approaches by situating them in the various local contexts and settings. After mapping and situating the various paradigms regarding research ethics in Germany, India, Greece, Brazil, and Russia, we outline a few basic principles of ethical research from a meta-reflective point of view. The ultimate objective of this document is to create a space for reflection on the ethical procedures and practices involved in obtaining, processing and disseminating data in accordance with fundamental principles and rules regarding data protection and privacy while taking under consideration the reliability and integrity of such data and their flow within cross-cultural, trans-national and global research contexts.

B. Written and unwritten rules & ethical practices in social-scientific research in Germany, India, Brazil, Greece, and Russia

B1. General attitude towards research ethics

GERMANY	Deontological approach – especially when researchers are involved in international research. Same codes and approach are employed in multi context research. Special focus on the anonymity of the field of research and of the research participants.
INDIA	Ethical skepticism approach is applied in that each researcher follows his or her instinct and knowledge in gaining the consent and the confidence of the participants. This entails common language and familiarity to the socio-cultural space. Consent varies: In medical research there are consent forms that the participants sign while in social science research consent is given verbally.
BRAZIL/ RUSSIA	Both deontological and ethical-skepticism approaches towards research ethics. In terms of the deontological approach, there is a national policy regarding research ethics in research involving human beings. However, researchers also follow an ethical skepticism approach which means that they make specific agreements with participants as to the ethical specific codes for each research plan they develop.
GREECE	Ethical skepticism approaches to ethics are most prevalent in that the majority of professional organizations and societies have not developed specific guidelines and principals for conducting research. Oftentimes, however, neither of these approaches is applied with the researcher's full conscious awareness. Research ethics are often a matter of the individual's conscience and the researcher does what he or she believes is 'right' and refrains from doing 'wrong.'

Summary: The deontological approach is adhered to for the most part by the teams. This implies that researchers generally identify and use universal code(s) in conducting research. The researcher is responsible for adhering to the codes. The Greek team described their context as having certain universal and general guidelines in conducting social science research, yet in practice researchers do not usually follow strict codes and rules. In India there are guidelines only for medical

research and there is skepticism with regard to ethical practices and procedures. In Brazil and Russia there are deontological codes for research which are generally applied but there is often negotiation with the participants regarding how strictly the codes are adhered to.

B2. Who is responsible for the ethical review of research projects in the various countries?

GERMANY Every researcher is expected to respect ethical rules in his studies and has to give a guarantee to the participants of his research that s/he will protect the personal data, and will not present or forward the data to third-member-parties of research or any other institution. Additionally if the research touches with specific laws, one has to apply for an ethical request and acceptance at the **ethic commission, which is either situated in the research institution itself** (i.e. university), or in **the funding agency** (i.e. DFG) or in the **professional associations** and/or by **particular institutions in the field** (i.e. local school administration). Occasionally ethical acceptance from an ethic commission is an official pre-requisite to conduct data or apply for funding. The researchers should submit a written application for this.

INDIA The social science research institutions, funding agencies and regulatory bodies have **not developed any ethical guidelines to be followed by researchers in social science research** other than the research ethics in general. JNU like other research institutes and universities has adapted ethical guidelines **on the lines of the biomedical research ethical guidelines** developed by medical research institutions like ICMR (Indian Council of Medical Research) and CEHAT guidelines. The researchers should submit a written application for this.

BRAZIL There are **university-based committees** as well as **funding agencies committees** that researchers are expected to get ethical clearance from. The researchers should submit a written application for this. There are specific institutions that permit research in public schools (pre-, primary, secondary, and tertiary): **If the project is conducted within a school, principals and boards of Education have to be contacted.** The project has to be presented and explained for approval.

GREECE There are **university-based committees** that researchers are expected to get ethical clearance from. The researchers should submit a written application for this. The University of Crete Senate recently adopted an institution-wide

Code of Ethics (Senate 229/22-3-12), founded a Institutional Review Board and adopted The European Charter for Researchers and Code of Conduct. There are **specific institutions that permit research in public schools** (pre-, primary, secondary, tertiary), the primary one is the Institute of Educational Policy (IEP). Yet, it is not mandatory for researchers to ask for review board approval to conduct their research, many research endeavors are not funded by European or Greek agencies or governing bodies, some disciplines have not developed guidelines, and universities have just recently establishing committees for the review of research proposals in the social sciences.

RUSSIA

Research in Russia is regulated by **legislation of Russian Federation and statutory documents of an organization where the research is conducted**. In accordance with the Federal Law of 22.08.1996 # 125-Φ3 “On higher and postgraduate professional education”, Federal Law of 23.08.1996 # 127-Φ3 “On science and federal research and technical development policy”, Statute for educational establishment of higher professional education (University), ratified by decree of Government of Russian Federation of 14.02.2008 #71 one of the purposes of the University is scientific development through carrying out fundamental and applied research in different areas such as general and professional education, innovational activity, and implementation of results into educational process. Control over the organization of scientific and innovation activities carried out at the university is delegated to: the vice-rector who is in charge of scientific work at the university, heads of educational, scientific and other departments of the university in accordance with the functions and powers. Evaluation of ethicality of a research proposal is conducted in accordance with the aforementioned clauses. Each research project is assessed and appraised by **experts mainly, the research supervisor, the scientific council of the laboratory or department**, and finally, the **Scientific and Expert Council** of the respective university.

Summary: The analysis of the information presented above reveals that in Germany researchers are primarily responsible for adhering to the universal guidelines. In India there are only ethic review boards for medical research. In Germany and Brazil there are university-based committees that review and approve research protocols and school boards/ or officials that review school-based research. In Greece there are national committees, university committees, and departmental committees that review and approve research protocols, but not at every university. There is a Ministry of Education committee that reviews research protocols that are conducted in schools. However, research has often been conducted without ethical review

board approvals. In Russia research is regulated by legislative guidelines from the Russian Federation and the statutory documents of the organizations where the research is conducted, and the primary responsibility is located with the vice-rector who is in charge of scientific work at the university and/or the heads of educational, scientific and other departments of the university. In summary, guidelines and procedures for reviewing research protocols do exist in the different settings, yet there is no monitoring per se in any of the countries involved in the DIGIT-M-ED project; this state of affairs often places most of the responsibility of adhering to guidelines on the researchers who interpret, apply, and balance the norms in different ways in light of their own values, priorities, exigencies, and experiences in the divergent research contexts where they work.

B3. What kinds of data are considered as “sensitive”? Is there a protection of sensitive data? In which law is this written?

INDIA	The right to protection of personal data is a civil and constitutional right. Article 21 of the Constitution of India provides for the right to life and personal liberty, which includes the right to privacy . The main laws regulating data privacy are the: Information Technology (Amendment) Act 2008 (IT Act) / Information Technology (Reasonable Security Practices and Procedures and Sensitive Personal Information) Rules 2011 (IT RSPSPPI Rules). The IT RSPSPPI Rules widen the scope of section 43A of the IT Act and regulates the collection, disclosure and transfer of sensitive personal data. In social science research usually the universal standards are followed in this regard.
BRAZIL	The Brazilian laws demand that any research conducted with human beings should involve ethical protection - Diretrizes e Normas de 196/96 do CNS (Conselho Nacional de Saúde/ National Council of Health)
GREECE / GERMANY	‘Sensitive data’ mean the data referring to racial or ethnic origin, political opinions, religious or philosophical beliefs, membership to a trade-union, health, social welfare and sexual life, criminal charges or convictions as well as membership to societies dealing with the aforementioned areas (Law 2472/1997, article 2, paragraph b).
RUSSIA	Confidentiality of information is ensured by Federal Law of 27.07.2006 # 152-Φ3 “On personal data”. In accordance with this law personal data is defined as any information related directly or indirectly to a specific physical person . In fact it means information that allows someone to identify this

person, and this information is concealed. In the scientific community it is customary to not disclose names and surnames of participants, and change them when reporting research results.

Summary: in most countries sensitive information includes: any identifying information such as a person's name; information about sexual attitudes, preferences, and practices; information about the use of alcohol and other drugs or addictive substances; information that can damage the person's standing or reputation within the community; information from the participant's medical records that can lead to social stigmatization or discrimination; and/or information about the participant's psychological well-being or mental health.

B4. What is a usual practice for a researcher or a research team to ensure that his or her/ their study is ethical?

GERMANY **Written explanation of the research purposes and written agreement** signed by every person who is involved in the research (for children under the age of 14 years, signature is required by their parents)

INDIA **There is no general rule or custom.** Gender, literacy, class, caste and religion issues must be taken into consideration.

BRAZIL A combination of a) **verbal explanation of the research purposes and oral agreement** of all people involved in the research and b) **written explanation of the research purposes and written agreement** signed by every person who is involved in the research (for children under the age of 18, signature is required by their parents); c) **informed consent** (both the researchers and the research participants sign). There is no difference in terms of gender, social class/ caste, literacy, religion or other factors. Researchers need to be sensitive to all kinds of people.

GREECE **Both verbal and written consent agreements can be used** depending on who is conducting the research, how they view, understand and adhere to ethical guidelines.

RUSSIA In the community of researchers it is customary to inform the participants of research (administration or teachers) **verbally** or in **written** form about the **goals** and **purposes** of the research, then on **results**. It is also customary to collect written consent from parents (legal representatives) of participating children to conduct research and render psychological assistance. It is also

common to mention the name of the establishment when publishing the results, if it elevates the status of this establishment. If possible, participation certificates and official gratitude letters are provided to the establishment.

Summary: Written informed consent is provided in some instances and verbal consent in others. This is obtained after the participant has had the opportunity to carefully consider the risks and benefits in participating in the study and to ask any pertinent questions. The researchers enumerate how privacy and confidentiality concerns will be approached. The Russian researchers provide feedback in accordance with the arrangements and agreements made when organizing the research and it is common in Russia to provide feedback to participants or teachers and administrators and to provide some form of consultation based on the research results.

B5. In case written agreement is required, what kinds of information does a consent form have to include?

GERMANY A list of names participants can contact if they have any questions, a statement that participation is voluntary and participants are free to withdraw at any time from the study.

BRAZIL Written consent by research participants means they know what participation in the study entails and that they choose to participate. The consent form entails information about: a) a statement clarifying the purpose of the **research endeavor**; b) description of any **potential risks or discomforts**; c) description of **potential benefits**; d) description of **confidentiality policy to be used**; e) a **list of names participants can contact** if they have any questions; f) a **statement that participation is voluntary and participants are free to withdraw** at any time from the study.

GREECE Consent forms contain the information that is pertinent to the study including the purposes, goals, objectives, procedures to be followed, confidentiality and anonymity standards, and the people involved in conducting the research. **Risks and discomforts are not always elaborated** upon or mentioned, yet there is mention of voluntary participation and possible withdrawal from the study. **Lists with the names of people to contact if they have questions are not usually included.**

RUSSIA The consent for participation in research is **written in free format**. Consent for processing of personal data is made out in accordance with demands of Federal Law of 27.07.2006 # 152-Φ3 “On personal data”.

Summary: Written consent in most countries includes a statement of the research purpose; a description of the potential risks and discomforts that may be involved in the study; a description of the potential benefits of the research; a description of the confidentiality policy that is to be applied in the research; and a statement that the participation is voluntary and that participants are free to withdraw at any time from the study.

B6. Is anonymity important in all local contexts? To which extent?

GERMANY	Very strict regulations for the maintenance of anonymity.
INDIA	In social science research anonymity is maintained . Yet in few cases participants may want their names presented or have their photographs and videos used in the reports. Maintaining anonymity remains a far most priority of all research especially in research dealing with stigmatized, sensitive or personal issues and information.
BRAZIL	In Brazil, participants can choose whether they want to have their names presented or not . In some cases, participants demand that they are presented.
GREECE	In the Greek context anonymity is ensured and participants do not want their names published or made public in any way.
RUSSIA	In Russia it is common and customary not to disclose names and surnames of participants but change them when exposing results of research, and to mention the name of the establishment where the research was conducted in publications of the research results only if it elevates the status of the establishment.

Summary: Cultural differences were apparent in the responses above. In Germany and Greece anonymity is very important and participants demand that it is carefully maintained. In India and Brazil participants may want their names presented. In Russia a lot depends on whether results and evaluations are positive or negative.

B7. How to use of visual data for research and knowledge dissemination purposes?

GERMANY

It is common sense between German researchers to not show any pictures of participants outside the scientific community and not to print clear photos in publications. Before using the camera, voice-recorder etc. in the field, **one has to ask for agreement** and acceptance and explain again the forms of anonymity. Sometimes a single person in a group setting might not want to be capture or recorded, this has to be strictly accepted. Also in the moment someone asks the researcher to stop capturing or recording, this has to be accepted in the very moment.

INDIA

How to deal with visual data is **not mentioned by the guidelines or laws** in India. Children and youth like to be photographed and filmed and often ask to participate. Women and girls usually do not like to be photographed and there are more difficulties involved with their participation in research. Older people may consent to photographs or video footage but usually inquire as to how these materials/ texts will be used. Their **consent is dependent on the nature of the enquiry**.

BRAZIL

The **consent for research with visual media is given in the same way as any other consent**. It follows the direction of the Diretrizes e Normas de 196/96 do CNS (Conselho Nacional de Saúde/ National Council of Health).

GREECE

This is something **not mentioned by the guidelines or laws**. In participatory action research where the subjects of research have ‘a say’ or ‘a voice’ in the project, participants would not mind being photographed especially in group photos or documentaries. In other research, where questionnaires or time consuming interviews are used people may not want to be audio or video taped. Young people are more likely to agree to the use of video or audio taping procedures while older participants are less likely to agree to such research methodologies.

RUSSIA

Photo and video is possible **if the administration and participants agree**. Confidentiality is regulated by Clause 152.1 of Civil Code of Russian Federation and Federal Law of 27.07.2006 # 152-ФЗ “On personal data”. Usually children like to participate in photo and video recording. Young girls and boys, and parents of the children react to it differently in different situations.

Summary: For the German team images should be altered and rendered not unidentifiable. The India and Brazil teams responded that consent is required and that participants often consent and want to be photographed or videotaped. In Greece there are no clear guidelines for consent in such research endeavors and it depends on the kind of research and who the research participants are if they would agree to take part in such research. In Russia there is a clause in the Civil Code regarding personal data that is also valid when referring to visual data. It appears that guidelines regarding visual data and images are less clearly outlined in the countries involved in the DIGIT-M-ED project and have been slow in being developed and enforced.

B8. Some particulars from the different settings

Monetary compensation is sometimes possible in medical research **in India**. In social science research this is a rare case. Participants expect that the researcher may compensate with advice, help or some social favors and, oftentimes, find it difficult to recapitulate. The social awkwardness constituted by this give and take can be rectified by discussing or publishing findings that are accessible to the participants.

In **Brazil** very often people dislike research that does not provide the group with results and does not help improve the school conditions. Research that describes problems and does not discuss and collaboratively try to find solutions with participants is generally not well accepted.

B9. Deontological underpinnings

Three major principles underlie most ethical research practices and considerations referred to above:

- a) The **principle of autonomy** refers to informed consent and freedom to participate or not participate in research. In other words this principle focuses on the rights of free will, privacy and confidentiality-securing the identity of, as well as any information provided by the respondent, in order to ensure to that

public identification of an individual participating in the study and/or his individual responses does not occur.

- b) Beneficence—**maximizing positive outcomes** and preventing harm is the second principle underlying the considerations presented above.
- c) The **principle of justice** refers to ensuring reasonable, non-exploitative and carefully considered procedures with fair distribution of costs and benefits for participants, researchers, and the disciplines involved. One of the crucial and distinctive features of this principle is avoiding exploitation and abuse of participants and the responses highlight this. The researchers' understandings and applications of the principle of justice in qualitative research studies is demonstrated by recognizing vulnerability of the participants and their contributions to the study. Justice is also adhered to when minority or vulnerable groups are listened to and when their voices are given credence in research. The DIGIT-M-ED project has this particular social justice focus.

C. Proposed guidelines and framework in cross-cultural/ trans-national youth research

C1. Introduction

Principles of research ethics are codified in a number of policies and documents, such as the UN Declaration of Human Rights, the Nuremburg Code, and the Declaration of Helsinki. The overriding ethical principles will be discussed in detail below and more detailed guidelines will be provided. The guidelines are based on the work Marcia Freed-Taylor, the Ethical considerations in European Cross-Cultural Research⁴, the Belmont Report⁵, the Ethical Considerations in Sociological research⁶, and the American Psychological Association's Ethical Principles of Psychologists and Code of Conduct⁷. To guide researchers, Emanuel, Wendler, and Grady (2000), Emanuel, Wendler, Killen, and Grady (2004), Wendler and Abdoler (2011), and Bhat and Hegde (2006) conducted reviews and synthesis of the most historically significant documents and ethical codes promulgated to date and identified eight requirements that must be met to ensure that research is conducted ethically.

Based on their publications and the guidelines founded by professional associations in order to outline an ethical framework for conducting transnational research, the framework below is intended to be used as a guide for reflecting upon ethical questions and dilemmas that are inherent in conducting field research in international settings. The text that follows outlines and discusses two different ways of thinking about scientific integrity in conducting social science research. The one viewpoint sees scientific integrity as a set of formal rules, conditions or requirements to be adhered to and met. These 'rules' are *externally imposed solutions* (for example, data protection regulations). The second viewpoint sees scientific integrity as a wider set of ethical concerns related to who we are as persons, social scientists and researchers. These *are internal or self-regulatory mechanisms*, practices and ways of conducting ourselves in our role as researchers. Hence, the guide is worded in such a way as to help the investigator convey to all involved in the research process how to adhere to the basic ethical research standards and behavior that accords with international ethical principles and guidelines and to concomitantly

⁴ www.unesco.org/shs/most

⁵ www.hhs.gov/ohrp/archive/belmontArchive.html

⁶ sociology.about.com/od/Research/a/Ethics.htm

⁷ www.apa.org

sensitize him or her so that the practices become part of his or her everyday practice and habitus. Users of this document are encouraged to translate it to their local language and to train or conduct discussions on ethical issues and dilemmas with team members at each location throughout the research process.

The guidelines provided are based on the 4 core principles provided by Freed-Taylor (1994) --Ethical Considerations in European Cross-National Research:

(a) the rights of participants: the need to protect the statutory rights of members of the social community or groups being investigated, avoiding undue intrusion, obtaining informed consent, and protecting the rights to privacy of individuals and the social groups who are taking part in the research process;

(b) the ethical conduct of research: the need to frame research questions and agenda objectively, so as to widen the scope of social science research focusing on digital media, and to maintain confidence in the research process; to ensure that the conduct, management and administration of research is framed in a way which is consistent with ethical principles and which recognizes the limits of competence of each member of the research team;

(c) Sensitivity to cultural and social differences: the need to remain sensitive to, and cognizant of, social and cultural differences and to consider conflicting interests;

(d) Reporting of research: the need to report findings completely, widely and objectively, with full information on the methodologies employed, keeping in mind that this allows research protocols and reports to be assessed by colleagues and increases public confidence in the study's reliability, validity, and general social value.

C2. What constitutes ethical interaction with human participants in qualitative field research?

What are the roles of the investigators?

Field research is an approach based on human interaction. Insofar as the data collected is the result of dialogical interaction between the researcher and the participants/ informants, field research entails a wide range of ethical issues that are complex and often unpredictable. The members of the research team who are collecting the data are responsible for making sure that the participants are fully aware of what the study entails and what they are agreeing to partake in. Moreover,

these team member(s) are responsible for collecting and storing data that is accurate and protected from loss or from confounding the privacy of the participants.

Field investigators themselves are the measuring instruments in that their experiences are recorded in field notes and analyzed during the data analysis and writing phases of the research process. This makes this form of research an interpretive- reflective process, and hence, the researchers' interpretations of the data are influenced by their values, point of view, personal history, and privileged status. All these factors impact upon the research process and on the ethical issues involved in the research. In order to avoid biases the researchers should state their pre-assumptions at the outset of the study and work to avoid bias in analysis or reporting of data.

Respect in conducting research

One of the primary ethical principles that are traditionally cited when discussing ethical concerns in research with human subjects is *respect*. *Respect* is a crucial consideration in conducting field research. Team members express respect for the goals of the research project, toward each other, each individual participant, the community or group of people that the participants represent, and the data collected in order to achieve the objectives and goals of the project. Respecting other's culture, gender, age, social class and caste, religion, sexual orientation and all other characteristics that make people different from each other is a crucial aspect of the research interaction. Respect is also expressed by maintaining a polite manner and thanking the participants for their time and effort.

Voluntary participation

People who decide to participate in a research endeavor should do so without coercion of any kind. People should not be required to participate in research, and hence, people have the right to refuse to participate or to terminate their participation at any point during the study. Moreover, participants may refuse to reply to questions that they do not feel comfortable in answering. Therefore, participants should not feel obliged to participate in research in any way. According to the influential Belmont Report (1979) *autonomy* is the primary ethical principal that all researchers must adhere to. *Autonomy* refers to the obligation on the part of the investigator(s) to respect each participant as a person capable of making an informed decision regarding participation in the research study. The investigator

must ensure that the participant has received a full disclosure of the nature of the study, the risks, benefits and alternatives, with an extended opportunity to ask questions. The principle of autonomy finds expression in the informed consent document.

Informed Consent

Another ethical principal in doing research with human subjects is autonomy, which refers to the obligation on the part of the investigator to respect each participant as a person capable of making an informed decision regarding participation in the research study. Informed consent, from persons capable of such consent, should be obtained in all research—whether this is written or verbal depending on the local context. Underage youth (in some countries this means teenagers who are 18 years of age and younger in other countries the cutoff age is 16) cannot provide consent for themselves and their parents and/ or guardians need to be consulted. This requires informing participants or their parents or guardians about the overall purpose of the research and its main features, as well as of the risks and benefits of participation. Information about the study should be presented to the potential participant in language that s/he can understand, and in a way that reveals the study's purpose, procedures, and the potential risks and benefits involved. The language and style of communication should enable a participant or his or her legal guardian to comprehend the processes and procedures involved in the research. Consent may be given in written format, verbally and audio-taped, or videotaped. The participant or his or her parent or guardian should be provided with the opportunity to carefully consider his or her willingness to participate and to ask any pertinent questions. That discussion should give the participant enough time to ask questions and to think about the decision whether or not to join or continue the study. Informed consent should be seen as an ongoing process where at different intervals during the study the researcher(s) explain the next phase or new procedures or where the participant is showing signs that s/he does not understand what is required. The investigator must enumerate how privacy and confidentiality concerns will be approached. Researchers must be sensitive to not only to how information is protected, but also, how participants should be debriefed/ informed about the findings.

In summary, informed consent implies *disclosure to the potential participant* or his or her parent or legal guardian as fully as possible of the nature and purpose of the research, the procedures to be used, and the expected benefits to the participant

and/or society, the potential of reasonably foreseeable risks, stresses, and discomforts, and alternatives to participating in the research. There should also be a statement that describes procedures that are in place to ensure the confidentiality or anonymity of the participant. An informed consent document is essential and in this document there should be a statement of the risk/ benefits and how possible adverse events will be handled, that is whom to contact in case assistance is needed at any time during the process or even afterwards (researchers' names and contact information or other people or agencies that may be of help in case of undue duress). Consent also includes assuring *understanding* by the participants of all that the research endeavor entails. The participants engage in research on a *voluntary basis* and should have the *competence* to give the consent required. A consent document is essential and most of the time it is important to obtain the signatures of the participants or their parents and guardians. In the Appendix of this document you will find a generic Informed Consent Form.

Enrolling participants who are considered vulnerable

Some participants require extra protection, and thus procedures need to be in place and must be followed in order to engage such subjects in a research project. The extra caution is necessary primarily because certain people, for example children, teenagers or people with certain disabilities may not fully understand the implications of the research or have parents or guardians who are legally responsible for them. Hence, research with children, adolescents or youth who are disabled or confront medical challenges involves getting permission or informed written consent from their parents or authorized caregivers. Parents who agree that their children can participate in a research study must always take the child's will into careful consideration.

Considering personal privacy in conducting research

Research participants have a right to privacy that the research team must take into consideration. The concept of privacy means personal information that is not publically expressed. There are cultures that do not give recognition to the concept of privacy, nevertheless, it is important in research that information pertaining to the participants should be protected. The research team should take all necessary measures to assure that personal information should not become privy to onlookers and that information that the participants do not want to share should be safeguarded. Privacy should also be protected by steadfastly avoiding embarrassing

participants. For example, interviews should take place in places where other people cannot hear the questions or the respondent's answers.

Assuring protection of Personal Information

'Personal data' is information that relates to an individual person. The individual can be identified from those data or from those data and other information. Such data includes any expression of opinion about the individual. In order to protect such information: 1) it has to be processed fairly and lawfully; 2) obtained and processed for specified purpose; 3) it has to be adequate, relevant and not excessive for purpose; 4) it has to be accurate; 5) it cannot be kept longer than necessary; 5) it has to be processed in accordance with the rights of data subjects, e.g. right to be informed about how data will be used, stored, processed, transferred, destroyed; right to access information and data held; 6) kept secure, and 7) not transferred abroad without adequate protection.

Personal information is protected by developing procedures for data coding, encryption, storage, analyses and management to minimize the potential for inadvertent breaches of confidentiality. In addition, it is protected by adhering to ethical procedures in dissemination of the findings.

Respect for the empirical and scientific basis of the study

Scientific integrity is a core value relevant to all research processes and activities. The integrity concept involves consistency of actions, values, measures, principles, expectations, and outcomes in conducting empirical research by well-trained researchers. Integrity also involves professional responsibility, trustworthiness, respect, caring, overall fairness and doing the right thing from the conception to the publication of the research.

There are several reasons why it is important to adhere to ethical guidelines in research. First, guidelines promote the purpose and objectives of research, which include finding answers to certain questions through the application of empirical procedures and, in this way, producing new knowledge. Second, ethical standards promote the values that are fundamental to collaborative work, such as trust, accountability, mutual respect, and fairness. Third, the ethical standards help to ensure that researchers can be held accountable for their work to the public at large and to the communities and participants that take part in the research. That is, ethical guidelines and policies on researcher misconduct, conflicts of interest, and the protection of participants are necessary in order to make sure that researchers who are funded by public money can be held accountable to the funding agencies

and the public. Fourth, ethical norms in research also help to build public support for it. People are more likely to participate in a research project if they can trust the quality and integrity of research. Finally, many of the norms of research promote a variety of other important moral and social values, such as social responsibility, human rights, fairness, and justice, compliance with the law, and health and safety. Ethical lapses in research can significantly harm participants, trainees (for example, graduate students), and the public.

The following is a summary adapted from Shamoo and Resnik (2009) of some ethical principals regarding the scientific integrity applied in conducting empirical research:

Honesty: entails truthfulness in proposing, performing, and reporting research entails candor in communications to colleagues, participants, granting agencies and the public and conscientiousness in conducting the research so that no fabrication, falsification, misrepresentation or deception of participants, data or publications takes place.

Objectivity: focuses on whether the methodological design, data analysis, data interpretation, and other aspects of the research is being presented in an accurate, clear, complete, and unbiased manner, and that theoretical perspectives and other 'bias' prone tools are presented and disclosed in a forthright manner. Objectivity is an ideal that can hardly be reached. Hence, the practice of trying to reach "objectivity" is an exercise in deliberately considering your topic, question, or interpretation from many different angles.

Integrity: defines the commitment of researchers to adhere to the fundamental rules of good scientific practice. Truth and transparency, self discipline, self criticism and fairness are indispensable for behavior of integrity. This implies keeping promises and commitments to research protocols approved by Scientific Review Boards, acting with sincerity, and striving for consistency of thought and praxis.

Being careful: in order to avoid errors in conducting requires the careful examination of one's own and the work of research associates in a studied and intentional manner. More specifically, reviewing research protocols and students or associates understanding of them and all the procedures involved. It also means keeping detailed records of research activities and procedures. Such activities include data collection, research design and methodology, and implementation practices, and keeping correspondence with all involved in the research process from participants, to agencies, to colleagues, and to journal editors. In order to adhere to the

principles and standards of practice inherent in the research endeavor a great deal of carefulness is necessary.

Openness: Social science research aims to create knowledge about how people interact and function in their unique worlds. Thus, social science research examines the public and private lives of people, including their ideas, beliefs, opinions, behaviors, emotions and attitudes—in essence their subjectivity or subjective experiences. This type of knowledge accumulates when researchers conduct studies and share their findings with others. Sharing allows other researchers to identify flaws or to extend the findings to expand understandings. Hence, the sharing of data, methodologies, ideas, tools and resources is essential if the discipline, which the researchers serve, is to produce valid, reliable and well documented results and understandings. Sharing in this fashion entails that researchers are capable of withstanding criticism and are open to changing and incorporating new ideas and methods.

Respect for intellectual property: In research this translates to honoring other people's work and their intellectual property. This entails not using unpublished data, methods or results without permission. It also means citing other people's work and giving them credit for their ideas, findings or publications. This form of respect means the avoidance of practices that lead to plagiarism.

Confidentiality: Informed consent is the process through which people decide whether or not to participate in social science research, and through which agreements are made concerning the handling of identifiable data. However, the regulations of human research, as currently written, are not very exact or clear as to how the protocol and informed consent relationship must be crafted in response to the manifold aspects of privacy and confidentiality in social research. Confidentiality can be defined as an explicit or implied guarantee by a researcher to a participant whereby the respondent is confident that any information provided to the researcher cannot be attributed back to him or her. Furthermore, the assurance of confidentiality carries with it the additional implication that non-researchers cannot discover the respondent's identity. Thus, confidentiality is an active attempt by researchers to remove any trace of respondent identities from the records. Confidentiality is an extension of the concept of privacy; it refers to data (some identifiable information about a person, such as demographic content or a videotape of the person) and to agreements about how data are to be handled in keeping with participants' interest in controlling the access of others to information about themselves. Boruch and Cecil (1979) write that privacy refers to persons and to their interest in controlling the access of others to themselves. Accordingly, this definition

recognizes the vital role of informed consent in giving research participants control over whether they will allow the researcher access to their lives and to their attitudes, behavior, beliefs, opinions and psychic world. It alludes to the two directions of access: a) information that is given to one or rejected by one, and b) information one reveals to, or withholds from, others, e.g., a subject's willingness or unwillingness to disclose personal details about his or her own life.

Responsible Publication: researchers publish in order to advance knowledge and scholarship in their chosen fields of interest. Hence, publications are meant to add new knowledge to the field of study and wasteful or duplicative publications should be avoided.

Responsible mentoring: students learn from educators and mentors behavior, especially their ethical or non-ethical conduct, values and praxis.

Social responsibility: social science research should strive to promote social good and prevent any form of harm to the participants and the public at large.

Competence: researchers should maintain and improve their own skills, knowledge and know-how, that it their expertise through continuing education, learning and transformation and should take all the necessary steps to protect the scientific integrity of their profession or field.

C3. Ethical sensitivity in conducting social science research

As social scientific research expands to involve diverse populations, contexts, and sensitive topics, it raises many complex ethical issues. These issues go beyond what is contained in textbooks or known to most researchers and Institutional Review Board (IRB) members and this is why ethical sensitivity is an ongoing process of constantly honing one's knowledge base as to develop critical skills in conducting ethical research, in applying the pertinent codes of professional conduct, in decision making, and in being socially and emotionally sensitized to the moral practices involved in conducting research. There are cultural, organizational, community, interpersonal, or personal dynamics that should be considered when making ethical decisions in the process of conducting research and this contributes to the relativity and complexity of the process. Moreover, it adds to the importance of continuing professional development. The literature on these issues is found in a variety of textbooks, guidelines from different professional organizations, and laws.

Understanding and solving some of these problems requires knowledge and resources that can be found via major libraries and on-line. Below there are several such resources listed. Yet, although codes, policies, guidelines, principles, and standards of practice are very important and useful, they do not cover every ethical dilemma researchers may come across, and almost always require considerable interpretation. It is therefore essential for researchers to learn how to interpret, evaluate, and apply all the different guidelines and how to make informed decisions as to how to handle the ethical issues that are inherent in research. This entails learning from each other, critical reflection, and open dialogue with colleagues. Moreover, it entails careful training of all researchers involved in conducting a study and careful monitoring of the entire research endeavour. A certain wisdom to conducting ethical research is acquired through this type of praxis, a praxis that adds to the global dialogue, is informed by the multiplicity of practices, codes, procedures and know-how that exists around the world, and that can inform and enrich social science research around the globe.

D. Links and resources for further information

The Convention of Human Rights and Fundamental Freedoms (1950)

<http://conventions.coe.int/Treaty/Commun/QueVoulezVous.asp?NT=005&CL=ENG>

The EU Charter of Fundamental Rights (2007) [http://eur-](http://eur-lex.europa.eu/en/treaties/dat/32007X1214/htm/C2007303EN.01000101.htm)

[lex.europa.eu/en/treaties/dat/32007X1214/htm/C2007303EN.01000101.htm](http://eur-lex.europa.eu/en/treaties/dat/32007X1214/htm/C2007303EN.01000101.htm)

You can find a small summary here:

http://www.europarl.europa.eu/charter/default_en.htm

The European Charter for Researchers and Code of Conduct

[European Charter for Researchers and Code of Conduct](#)

[Europahttp://ec.europa.eu/eracareers/pdf/eur_21620_en-gr.pdf](http://ec.europa.eu/eracareers/pdf/eur_21620_en-gr.pdf)

The Nuremberg Code (1949).

<http://www.hhs.gov/ohrp/archive/nurcode.html>

The Universal Declaration of Human Rights

<http://www.un.org/en/documents/udhr/>

The UN Convention on the Rights of the Child

<http://sithi.org/admin/upload/law/Convention%20on%20the%20Rights%20of%20the%20Child.ENG.pdf>

The United Nations Covenant on Civil and Political Rights

<http://www.hrweb.org/legal/cpr.html>

The United Nations Covenant on Social, Economic and Cultural Rights

<http://www2.ohchr.org/english/law/cesscr.htm>

American Anthropological Association (AAA). (1998). *Code of ethics of the American Anthropological Association*. Arlington, VA: AAA. Retrieved May 13, 2008, from <http://www.aaanet.org/committees/ethics/ethcode.htm>.

The American Psychological Association's (APA) Ethical Principles of Psychologists and Code of Conduct (2010). www.apa.org

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APPENDIX: Exemplary Informed Consent Form

Informed Consent for the Research Project: **[TITLE OF THE PROJECT]**

Principle Investigator: **[NAME]**

Researcher 1: **[NAME]**

Researcher 2:

University of **[NAME]**, Department of **[NAME]**

Review Board Approval: **[DATE, NUMBER ON THE APPROVAL LETTER]**

**What is the goal
of the study?**

The suggested research project has the following scientific objectives:

- a) to explore how young people from urban marginalized neighborhoods employ digital video capturing, editing and sharing media
- b) to promote theory building about video-editing digital media, marginalized youth development and education
- c) to support and develop interdisciplinary training for the understanding of digital media and technologies practices
- e) to investigate differences regarding emerging media practices between European countries, Brazil and India.

What will participation in this study imply?

**Voluntary
Participation**

Participation in this study is voluntary and the young people may stop participation at any time, without caregivers/legal guardians or the young participants being asked to provide reasons for their decision to terminate their participation.

**Research
Process**

In close cooperation with the young people, **[NAMES]** intend to do participant observation for at least four days a week over the course of one month, observing different media-related practices in different settings, such as home, street, after-school programmes. The participant observation will consist of writing field notes and if appropriate interacting through interviews, and photography/video of/by the young people. It will also be complemented with open-ended interviews.

**Data affected by
privacy issues/
Video & Audio
Recordings**

All observations, information about the living conditions and location of the people involved in research as well as all statements and recordings will be made under a different name, with individual details being modified so that no individual will be able to be recognized. In order to better concentrate on conversations and interactions with the young people, the researcher would like to be able to record them. This will allow the researcher to better reconstruct young people's answers and reactions during the data analysis, making sure that what young people say and how they act is well understood. Material collected during the research will be used solely for purposes of academic analysis. Visual material will only be used for training purposes. The identity of the young people will be treated with utmost confidentiality. All of their statements will be kept secure and will only be accessible to the researchers. Parents may ask that recordings or transcriptions of their children be deleted at the end of the study, or, if the young person terminates, as soon as the young person ceases to participate.

**Who will
conduct the
study?**

Example: This research is funded by the European Commission. Dr. [NAME] studied psychology and anthropology in Greece and Germany. He has organized and conducted a series of projects with children and young people. Dr. [NAME] works at the xxx. For more information, please see: [webpage of the project]

Thank you for taking the time to read this information. For questions about the research, you may contact me at any time.

Contact: Dr. [NAME], Tel: [XXX] Email: [XXX]

I have read and understood the information about this research project and consent to my (child's) participation.

Participant's Name:

Place, Date:

Signature

I consent to adhering to all procedures and principles as described above.

Researcher's Name:

Place, Date:

Signature