meSch
Material Encounters with digital Cultural Heritage

Material EncounterS with digital Cultural Heritage

FP7-ICT-2011-9: 600851

– Deliverable D9.2 –

'Guidelines to Conduct Ethical Research'

SEVENTH FRAMEWORK PROGRAMME

Document Information

Document	**meSch _D9.2_SHU_WP9_ Guidelines to Conduct Ethical Research**
Revision:	**V2.0**
Date:	**31/05/2013**
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Security:	Public

Document Information

Consortium, European Commission

Approvals

Date	Partner
27/05/2013	FBK

Document History

Version	Date	Comments & Status	Author
V1.0	19/05/2013	Draft	Luigina Ciolfi
V.1.1	27/05/2013	Draft	Luigina Ciolfi, Ornella Mich
V1.2	28/05/2013	Draft	Luigina Ciolfi, Eva Hornecker
V2.0	30/05/2013	Final	Luigina Ciolfi, Eva Hornecker

List of Beneficiaries

Beneficiary Number	Beneficiary name	Beneficiary short name	Country
1 (coordinator)	Sheffield Hallam University	**SHU**	United Kingdom
2	University of Limerick	**UL**	Ireland
3	Stichting Waag Society	**WAAG**	Netherlands
4	University of Strathclyde	**UoS**	United Kingdom
5	ECTRL SOLUTIONS SRL	**ECTRL**	Italy
6	Stichting Digitaal Erfgoed Nederland	**DEN**	Netherlands
7	Universitaet Stuttgart	**USTUTT**	Germany
8	Universidad Carlos III De Madrid	**UC3M**	Spain
9	Museo Storico Italiano Della Guerra	**MdG**	Italy
10	Universiteit Van Amsterdam	**UoA-APM**	Netherlands
11	Stichting Museon (Museum Voor Het Onderwijs)	**MUSEON**	Netherlands
12	Fondazione Bruno Kessler	**FBK**	Italy

Table 1. List of Beneficiaries

Table of contents

1 EXECUTIVE SUMMARY

Deliverable D9.2 provides an overview of issues and guidelines related to conducting ethical research within the meSch project. It describes the main areas of the meSch workplan that require particular attention to ethical considerations and provides consortium-wide procedures for ensuring ethical approval of research activities.

Reference Documents

Internal Documents
meSch - Description of Work

Other Documents
Bryman, A. (2012), *Social Research Methods*, Oxford: OUP

European Commission (1995), Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data, *Official Journal of the European Communities L 281, 23/11/1995 P. 0031 - 0050* Available at:
http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:31995L0046:en:HTML

European Commission (1997), Directive 97/66/EC of the European Parliament and of the Council of 15 December 1997 concerning the processing of personal data and the protection of privacy in the telecommunications sector, *Official Journal of the European Communities L24, 30/01/1998 P. 0001-0008*. Available at:
http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:1998:024:0001:0001:EN:PDF

European Commission (1998), 98/560/EC: Council Recommendation of 24 September 1998 on the development of the competitiveness of the European audiovisual and information services industry by promoting national frameworks aimed at achieving a comparable and effective level of protection of minors and human dignity, *Official Journal of the European Communities L 270, 07/10/1998 P. 0048 – 0055.* Available at:
http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:31998H0560:EN:HTML

European Commission (2001), Regulation (EC) No 45/2001 of the European Parliament and of the Council of 18 December 2000 on the protection of individuals with regard to the processing of personal data by the Community institutions and bodies and on the free movement of such data, *Official Journal of the European Communities L8, 12/01/2001 P. 0001-0022.* Available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2001:008:0001:0022:en:PDF

European Commission (2009), "Data protection and privacy ethical guidelines", Ethical Review in FP7, 2009 http://cordis.europa.eu/fp7/ethics_en.html

Langheinrich, M., Schmidt, A., Davies, N., José, R. (2013), "A Practical Framework for Ethics – the PD-Net Approach to Supporting Ethics Compliance in Public Display Studies", Proceedings of PerDis 2013, Mountain View, CA. New York: ACM

Orb, A., Eisenhauer, L and Wynaden, D. (2000), "Ethics in Qualitative Research", *Journal of Nursing Scholarship* 2000; 33:1, 93-96

2 SPECIFIC AREAS OF ETHICAL CONCERNS FOR MESCH

This deliverable details the guidelines for conducting ethical research within the meSch project. We outline a consortium-wide checklist for conducting ethical research that must be taken into account by each partner in conjunction with following their institutional regulations for ethical approval of research activities involving human subjects (where these exist).

Due to the breadth of the consortium and of the different types of activities to be undertaken in the project workplan, we identify major areas requiring ethical considerations, and the specificity of issues relating to them: logging and personalisation via meSch tools and systems; co-design activities and other events; experimental user studies of meSch technologies. These are briefly outlined in the following short sections.

2.1 Logging and personalisation via meSch tools/systems

User tracking and personalization services by their very definition require collection of information about users' interactions with the system, and possibly personal features relevant for the process of personalization (e.g., interests, age, social context). These facilities for data collection need to be developed so as to be **directly customizable as needed**, to **guarantee data security and privacy**, and to ensure that **users and stakeholders maintain the control** over collected data.

2.2 Co-Design activities and other events

The project will evaluate its methodological approach of co-design and thus will conduct a retrospective analysis of co-design activities and other events (such as FabLabs and Authoring Feasts) that involve project partners, other stakeholders and potential future users. **Informed consent by participants** at such events is required for data collection. **Invitations** to these events **will inform potential participants of the procedures for documenting activities and participants' opinions**, and will allow for early discussion over questions and concerns that participants may have. Moreover, analysis and reporting based on data from co-design activities need to be conducted in a considerate way that shows respect for participants, since co-design relies on the building of trust between partners in an on-going relationship.

2.3 Experimental user studies of meSch technologies

This includes all empirical studies of specific technologies, including for example lab-based studies of the usability and efficiency of meSch tools that will be conducted at various stages of the project. It also includes informal tests of smart object prototypes involving end users. The experiments and user studies involving technology must not pose any health and safety risks. They are also expected not to elicit sensitive personal information from the participants. **Standard procedures for informed consent, anonymisation of data, etc.** will be employed in preparation for these activities.

2.4 In-situ evaluation at museums sites of public exhibitions

meSch will utilize public exhibitions for the early deployment of meSch technology. Evaluation activities will monitor: the curators' use of the meSch authoring environment and embedded multi-sensor system platform in developing the exhibitions (issues here are similar to those mentioned under Co-Design activities in WP1); and how visitors interact with and react to the kinds of adaptive smart objects and personalization services enabled by meSch technology. In the latter case, participants will be members of the general public within a public setting.

Evaluation techniques need to be **as unobtrusive as possible** so as not to interfere with visitors' aims and their experience of the site. However, the **participants' informed consent** needs to be ensured, as well as the protection of the **privacy rights** of participants and of data relating to them. **If it is not possible to obtain individual informed consent** (for example due to the large number of visitors), notices will have to be placed at the exhibition sites informing participants of evaluation activities and of which data collection techniques will be employed.

For all studies pertaining to one of the specific areas of meSch work, **the main partner** undertaking them **will identify a responsible person** to be available for explaining the details of the study to participants and stakeholders if they so require. In case the responsible person is not the meSch named Scientific Contact Point for that institution, both names will have to be indicated in all the ethical documentation related to the study.

3 ETHICAL CHECKLIST AND PROCEDURES

All partners, independently of whether their institution provides an internal process for ethical approval based on national laws and guidelines, are required to consider a set of guidelines for the ethical treatment of subject data and for the obtainment of informed consent in studies involving human subjects, as stated in the European Commission documentation on Ethics in FP7 (European Commission, 2009).

3.1 Ethical checklist on data privacy and protection (adapted from the European Commission documentation on Ethics in FP7)

In planning research studies involving human subjects, the following checklist (adapted from the European Commission documentation on ethics in FP7) (European Commission, 2009) must be considered and provided for: clarifying what type of personal data will be collected, used and/or stored within the research study;

- Clarifying what kind of human participants (adults, elderly people, children, etc.) will be involved within the research study and whether they may be sensitive subjects (e.g. children, etc.);
- Ensuring that all sensitive data that are planned to be collected are really focused on the research question and relevant for the foreseeable research;
- Specifying for how long will the collected data be used;
- deciding how the collected data will be stored and when they will be irreversibly destroyed;
- Making sure the researchers have the necessary legal permission to obtain and process the data (also considering national rules and the rules of their institution);
- Specifying how the collected personal data will be securely accessed;
- Specifying how the data will be securely stored, both in terms of data structure and format and of location and hardware;
- Planning how the data will be securely transferred if necessary (to other partners, reviewers, etc.).

3.2 Ethical guidelines on Informed consent

The potential participants must be given sufficient information in order to choose whether or not to participate. This should be based on an understanding of the risks and alternatives in an environment, and be free from any coercion. The participant needs to agree to participate and that her/his data will be used for a specific research scope. The participant will be aware of the meaning of such use.

Individuals recruited for the studies may request further details regarding:

- Methods used for collecting and handling personal data (e.g. observations, questionnaire, interview, etc.);
- Justification for requesting/obtaining their data (e.g. use in research development, etc.);
- Duration of data use and storage;
- Guarantees concerning the rightful use of data;
- Their right to inspect data pertaining to them and to withdraw from the study.

In terms of the researchers' attitude towards participants and their overall attitude in conducting empirical research, a professional and respectful code of conduct is to be expected at all times. We refer to the professional code of conduct outlined in the ACM Code of Ethics (www.acm.org/constitution/code.html) as adapted by Langheinrich et al. (2013) for a FP7 multidisciplinary project –PD-Net- similar to meSch.

All meSch partners are also to familiarise themselves with the detailed guidelines described in the CORDIS recommendations on Ethics for FP7 (http://cordis.europa.eu/fp7/ethics_en.html) and summarised in the checklists above.

4 PARTICIPANTS

We expect that **most participants in meSch studies will be healthy adults**, consisting mainly of cultural heritage staff (curators, educators, exhibition designers, artists) and members of the general public visiting the museums/heritage sites. While the project does not aim at explicitly involving vulnerable participants who need special consideration and protection (children, disabled people, etc.) nor investigates topics that are of an intrinsically sensitive nature (such as sexuality, political preferences, etc.), **privacy protection is nevertheless paramount**: e.g. observed conversations at heritage sites may contain private information where disclosure may harm the participant. Moreover, recording co-design workshops and observing and recording users' interactions at case study sites creates data that can allow for the identification of participants in imagery or video. Ensuring anonymity and privacy will be essential for all these activities.

The rights and interests of research participants must be weighted against the research goals and benefits at all times. Therefore, safeguards will be adequately adopted to satisfy compliance with ethical principles. Comfort and safety of all participants who take part in study in the different scenarios and locations of use must be guaranteed, as well as the security of their personal data. Attention will be paid to ensuring that **participation in research is a positive and rewarding experience**.

Whereby partners establish a long-term collaboration with a heritage institution or other group or community of stakeholders, they are to clarify the conditions of such collaboration upfront, and must commit to continuously apply ethical guidelines throughout the collaboration.

All partners are to carefully address the protection of human dignity in compliance with the Commission's Directives 95/46/EC, 97/66/EC, the Council's Recommendation 98/560/EC, the Regulation No 45/2001 and related national laws, such as the UK's Data Protection Act 1998 or the Italian 'Decreto legislativo 196/2003 Codice in materia di protezione dei dati personali', on the protection of individuals personality and privacy rights with regard to the processing of personal data and on the free movement of such data.

The above-mentioned directives must also be taken into consideration when designing and implementing the information repositories of meSch technology.

All national legal and ethical requirements of the Member States where the research is performed must also be fulfilled when requested by the individual partner institutions.

Project partners will **seek approval of their University's or Institution's ethical clearance procedures** (such as University Ethics Committees) where these exist (see Section 5), and if appropriate/required, **local governments privacy regulators**. Procedures for evaluation activities and data collection will be **tailored according to privacy regulations** in the respective countries that studies are conducted in. This concerns e.g. video recording of human activities, or the participation of children, as well as storage of and access to data.

5 ETHICAL APPROVAL PROCESS

When planning a study involving participants, all meSch researchers are asked to do so against the **checklists detailed in Section 3**, and to make sure all the checklist items are appropriately addressed. In particular, researchers must **ensure that informed consent is given**, either by providing participants with a specific informed consent form or, if using a survey and/or questionnaire, this can be embedded into the documentation, or by making available public notices in public places with information on the study.

For partner institutions that have an ethical approval process in place, meSch researchers will follow such process and will then file the ethics application and related institutional approval to the meSch Sharepoint site. For those partner institutions who **do not** have an internal ethical approval process in place, researchers will **fill the form outlines in section 5.1 and submit it to the meSch project administrator for quick review** (max 5 days), and then file it on the meSch Sharepoint. The project administrator (Mrs. Helen Grantham) will make sure that all the checklist issues are provided for before the study commences. If it appears that the checklist is not provided for and/or that there are any other critical issues with the proposed study, the form will be passed on to the Project Coordinator (Dr. Daniela Petrelli) for further review and advice to the proposers.

In Summary, when you plan a study involving participants, you have to:

- outline ethical details of the study according to the checklists in section 3.1;
- if your institution has an internal ethical approval process, proceed to submit your proposal to it;
- once approval is received, file all documentation (both submission and approval) on the meSch Sharepoint site;
- if your institution does NOT have an internal ethical approval process, fill in the form in Section 5.1 and submit it to the meSch administrator (Helen Grantham) for quick review;
- if the proposed study doesn't address all the guidelines in the ethical issues checklist, revise your proposal following feedback and advice by the mesch project administrator and coordinator;
- once internal approval is granted, file all documentation on the meSch Sharepoint site.

5.1 meSch Internal Ethical Approval Form

Name of Researcher	
Name of Principal Investigator (if different)	
Partner Institution	
Email address	
Title of Proposed Study	
Brief Outline of Proposed Study (rationale, aims, methodologies to be used, recruitment methods, timescale)	
List of Stakeholders and/or Organisations that the study will involve (if any)	
Adherence to data protection and informed consent checklist (outline the steps you have taken for each item of the checklist)	
Any other useful information	

Once complete pass this form to the meSch administrator for quick review.

Approvals

Date	Reviewer
	<meSch project administrator>
	<meSch project coordinator (only if necessary)>

6 SPECIFIC APPLICATION OF GUIDELINES

Consent forms and other data files that permit identification of participants will be kept separately and will only be connected to raw data via unique identifiers. Data will be saved to encrypted storage devices and physically stored by each partner responsible for its collection in a locked storage unit at their institution (e.g. safe data storage cabinet) for a maximum period of 7 years and/or in compliance with local national regulations. If any of the other meSch partners require a copy of the original data for purposes related to the work plan, they will also provide a locked storage facility for the data. Responsibility for data storage will be with the principal investigator from each partner institution. Access to data will be restricted to project members. Data will be safely deleted in accordance with EU laws and national regulations.

The above relates to all cases involving data collection outlined in the following sections.

6.1 Ethical issues related to tracking, logging and personalisation

Personalisation and contextualisation, by their very nature, involve taking advantage of information about users needs, interests and context of interaction to (i) guide the extraction, analysis and appropriate presentation of information and to (ii) adapt the interaction to maximise relevance, appropriateness, usefulness and experience quality. Therefore, specific measures need to be properly taken into account to preserve users' privacy and to avoid data misuse throughout the information flow.

During the implementation of the meSch project and in the research activities arising from it, all the ethical and social risks deriving from the manipulation of personal and contextual data must be carefully dealt with (i) in accordance with Local, National, and Community laws, and (ii) by correctly and constantly taking acceptability, usability, sense of comfort, control and privacy into account to inform the technological solutions developed.

The meSch multidisciplinary team of researchers, technical developers and cultural heritage stakeholders must work in close collaboration throughout all work packages to assure that the developed technology addresses the principle of proportionality, i.e. user data are collected and processed only insofar as they are adequate, relevant and not excessive in relation to the purposes for which they are collected and for the expected benefit for the technology end user. Wherever possible, data will be anonymised or pseudonymised at the earliest possible stage, by replacing personal identification with unique pseudonyms and IDs.

The personalization methods, algorithms and services developed within the project will aim at being accessible, not harmful, and suitable to guarantee data security and privacy (WP3, WP4)..Information will be deleted after necessary usage and will not be recorded or transmitted unnecessarily. Automatic transmission of anonymised user data will take place only between the components of the meSch system for the purposes of delivering the meSch services. All components and transmission channels will be secured to avoid unauthorized access. Data access for research purposes will be allowed to authorized personnel only, belonging to the consortium partners who have adhered to the ethical protocol.

Users and stakeholders will maintain control over collected data, being informed at their request of where the information (interaction logs and user models) is stored and whether it is transmitted, who has access to it, with the possibility of inspecting and requesting the cancellation of all personal data even before the programmed cancellation of the data at the end of the project (WP3).

Project results about log analysis will be disseminated preserving anonymity and presenting data in an aggregated form.

6.2 Ethical issues related to co-design and other events

Concerning co-design events, FabLabs, Authoring Feasts and other workshop-based activities described in WP1, WP6 and WP8, the modalities in which the participants' activities will be monitored and documented will be made clear in writing before the event. Participants will receive **information sheets** outlining the event/activity, the data collection strategy and how this data will be used for the research. It will be made clear in the information sheets that participants will have the right to withdraw from the event at anytime should they wish to do so. **Data collection** will only be conducted with prior (written) informed consent. Event organizers will devise strategies to ensure that the collected data can be used for research purposes and for documentation of events for dissemination purposes, while respecting the participants' privacy rights. This can include, for example, different levels of consent (participants can volunteer for their imagery to be used), using separate video cameras to record the overall workshop and for dissemination-purposes, and providing participants with a preview of imagery before publication for approval.

6.3 Ethical issues related to user studies and experimental studies

The participation in formal evaluation studies will be entirely voluntary, with prior written consent given for data collection, following standard procedures. Data from such evaluation studies will be **anonymised** (apart from particular cases where identification is necessary for the research question and provided that explicit consent for identification is given by specific participants). Recruitment may follow a snowballing strategy starting from project partners and existing contacts in order to reach potential future users. Other channels can also be utilised, for example subject-specific mailing lists on cultural heritage, community events, etc. and similar other forums that the meSch partners have access to (e.g. interest groups, community stakeholders, etc.).

6.4 Ethical issues related to in-situ evaluations

In the meSch pilots and case studies, observational studies will be conducted in **public settings** where participants can expect to be observed by third parties. In this case, explicit consent is not always considered necessary, if the behavior of those observed is not altered by the study and their privacy is respected (see FP7 guidance for Researchers and Evaluators of Social Sciences and Humanities Research, http://cordis.europa.eu/fp7/ethics_en.html). Following established procedures in e.g. sociological research, visitors to the sites will be informed of the research taking place, of its purposes, modalities and of their rights to access data pertaining to them. Researchers being present on site to conduct observations **must wear identification** making clear their association with meSch and their role. Evaluation activities will be as **unobtrusive** as possible so as not to interfere with the site visit, and with the users' experience of the site. This is not only important to guarantee that observational findings are not an artefact of the study setup, but also to minimize the burden of partaking in the research for visitors.

Video observations may be used as a data gathering technique. In that case, depending on the location of the research, **national law** may requires explicit written informed consent for video recording, and meSch research procedure will have to be adjusted to adhere to this. meSch researchers intending to use this methodology must clarify the rules and possible constraints on video recording during the planning phase of the study.

If prior written consent by all visitors to a facility is not feasible, a proven method is the 'shadowing' of volunteers.

Special procedures must be followed for **recording during school visits** to a field site (museum), which vary depending on the country (parental consent, approval by school boards etc.). When planning a study involving children, meSch researchers must ensure they comply with their institution's rules regarding ethical research involving children and with the national law.

Visitors must be provided with full information about the project aims, data capture and usage. Even though the project does not focus on **vulnerable persons as users**, these may often be present in museum settings (e.g. children) and constitute a natural and integral part of this settings' social dynamics. In many cases minors would be accompanied by a caretaker or legal guardian who can provide informed consent. However, if informed consent is not feasible, recording will be suspended.

While the project does not aim at eliciting information that is of an intrinsically sensitive nature, there is always a risk that e.g. a recorded conversations may contain privacy-sensitive information. Even with informed consent for the use of data, the research team needs to deal with such information in a considerate way. For this reason, transcripts will usually be **anonymised for publication** and, in cases where sensitive anonymisation is not possible, edited to omit references to sensitive content.

As part of the pilot exhibitions, log files and online tracks by visitors will be evaluated and analysed in order to evaluate the personalisation services and the impact on the use of online resources of visits.

Every installation will furthermore have to be planned against the respective **museum's health and safety regulations**. Moreover, there will be a health and safety check performed by the museum designated health and safety officers in collaboration with meSch researchers prior to the opening of the exhibition featuring meSch technology to the public.

7 CONCLUSIONS

This document has provided: 1) an overview of meSch areas of particular ethical concern, 2) a set of guidelines for the ethical treatment of participants and of data arising from the research and 3) specific indications on how such guidelines are to be applied in particular cases.

In summary, prior to undertaking work involving human participants, meSch researchers will have to:

- review ethical guidelines for professional conduct (see Section 3.2);
- prepare documentation for obtaining ethical clearance from each body/institution, following institutional guidelines and making sure the ethical guidelines with regard to data privacy and protection are addressed in the application;
- if an institution does not have an internal process for ethical approval, submit the form in section 5.1 to the meSch project administrator for quick review;
- submit ethical approval application and notification of institutional approval to the meSch Sharepoint (see section 5.1);
- comply with ethical guidelines on data storage, anonymisation and transfer (see Section);
- maintain a professional and ethically-aware conduct during every meSch study involving human participants (see Section 3.2).