Ethical and data protection issues are very high in the EXPERIMEDIA goals. Therefore the project identified an ethical issues coordinator, as well as a data protection coordinator, which will be incorporated within the overall project management structure. Additionally, an Ethics Advisory Board (EAB) and Data Protection Board (DPB) will be created. The former will advise the EXPERIMEDIA consortium on ethical, privacy and data protection issues, while the latter is responsible for ensuring that EXPERIMEDIA is compliant with data protection requirements and that the technical partners develop a system that considers privacy. This present deliverable describes the terms of reference for the EAB and the DPB, including their initial membership composition, mandate, operating procedures and meeting procedures. Furthermore, this deliverable contains an overview of the ethical oversight principles that should be taken into account by the EAB and DPB for each experiment. Finally, his deliverable contains definitions of relevant notions for the EXPERIMEDIA project.
EXPERIMEDIA

Project acronym: EXPERIMEDIA

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Work programme topic: Objective ICT-2011.1.6 Future Internet Research and Experimentation (FIRE)

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Project duration: 36 months

Activity 1: Legal, sustainability and promotion

Workpackage 1.1: Legal, ethical and regulatory framework

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<tr>
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<td>Updated front page and meta-data; added conclusion</td>
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1. Introduction

EXPERIMEDIA will conduct research with human participants and is, in particular, interested in human behaviour and experience with Future Internet technologies to understand how to provide meaningful collective experiences to individuals and society. Given that participants in social and networked media research should have confidence in the experimenters, good research will only be possible if there is mutual respect and confidence between experimenters and participants. As some areas of human experience and behaviour may be beyond the reach of experiments, observation or other form of investigation and may raise ethical considerations, EXPERIMEDIA will provide an ethics management process that incorporates ethical and data protection review of experiments.

Appropriate management of ethical issues will be guaranteed by the project management through a mixture of measures to ensure the right technical, physical and administrative environment. The project identified an ethical issues coordinator, as well as a data protection coordinator, which will be incorporated within the overall project management structure. Additionally, an Ethics Advisory Board (EAB) and Data Protection Board (DPB) will be created. The EAB will advise the EXPERIMEDIA consortium on ethical, privacy and data protection issues. The DPB is responsible for ensuring that EXPERIMEDIA is compliant with data protection requirements and that the technical partners develop a system that considers privacy. This document describes the terms of reference for the EAB and the DPB, including their initial membership composition, mandate, operating procedures and meeting procedures. Furthermore, this deliverable contains an overview of the ethical oversight principles that should be taken into account by the EAB and DPB for each experiment. This document also contains definitions of relevant notions for the EXPERIMEDIA project.
2. Ethical Issues Coordinator

The Ethical Issues Coordinator (EIC) will coordinate all issues related to ethical aspects of the research and is responsible for ensuring that all experiments are conducted in accordance with ethical principles. The role of the EIC will be assumed by Professor Jos Dumortier (K.U.Leuven) and will be assisted by the EAB.
3. **Data Protection Coordinator**

The Data Protection Coordinator (DPC) will coordinate all data protection aspects of the project and will be the main person responsible for liaising with the relevant data protection authorities and notifying them in case of a processing operation. The DPC, in collaboration with other project partners that will be involved in the experiments, will carry out the administrative task of dealing with data protection issues. The role of the DPC will be assumed by Professor Jos Dumortier (K.U.Leuven) and will report directly to the EAB.
4. Ethics Advisory Board – Terms of Reference

4.1. Mandate

The EXPERIMEDIA consortium has established the Ethics Advisory Board (EAB) with the aim to provide advice to the EXPERIMEDIA consortium on ethical, as well as privacy and data protection issues. In this way it will be ensured that the EXPERIMEDIA experiments are in line with existing ethical and privacy policies.

The mandate of the EAB is (based on the ethical principles for EXPERIMEDIA – see below):

- to review (using a proportionate approach), approve, reject, propose modifications to, or terminate any EXPERIMEDIA experiment,
- to ensure that EXPERIMEDIA is compliant with data protection requirements,
- to ensure that the technical partners of EXPERIMEDIA develop a “socially acceptable” system that considers privacy,
- to conduct an ethical review of each driving experiment using the EXPERIMEDIA facility,
- to conduct an ethical review of each open call experiment using the EXPERIMEDIA facility,
- to provide ethical oversight for experiments using the EXPERIMEDIA facility,
- to assess the informed consent form of each experiment.

The EAB should as a minimum consider the principles of:

- ‘doing good’,
- ‘doing no harm’,
- risk management, which encompasses the assessment of hazards (i.e. source of potential harm) and an analysis of risk (i.e. the probability of such harm occurring),
- consent,
- confidentiality,
- data protection (through liaison with the Data Protection Board).

Where the EAB is unable to resolve a particular issue, including any concerns of an ethical or related nature raised by participants in an experiment, the Ethical Issues Coordinator will relay all relevant details to the Executive Board of Activity Leaders chaired by the General Manager.

4.2. Operations of the EAB

The communications between the EXPERIMEDIA consortium and the EAB will be based on workshops and exchange of documents:

- EXPERIMEDIA will organise an EAB meeting approximately every 6 months. A total of 6 meetings over the project duration of 3 years are envisaged. In order to increase the opportunities for exchanges between the consortium and the EAB members, it is
intended to organise the EAB meetings in parallel (same time, same location) with specific consortium meetings.

- A private website will be set-up to facilitate communications and sharing of information between the EAB and the consortium. It will contain documents produced by EXPERIMEDIA for review by the EAB and also support closed fora for on-line discussions.

As regards its relation to the consortium management organisation, the EAB will have an advisory status.

4.3. Membership

The EAB will be composed of external independent experts in ethics and data protection in complimentary disciplines which are to provide appropriate guidance and review:

Table 1. Members of the Ethical Advisory Board.

<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
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<tbody>
<tr>
<td>Mrs Marit Hansen</td>
<td>Independent Center for Privacy Protection Schleswig-Holstein – ULD (Germany)</td>
</tr>
<tr>
<td>Dr Mireille Hildebrandt</td>
<td>ICIS-Radboud University Nijmegen (The Netherlands)</td>
</tr>
<tr>
<td>Dr Jeanne-Pia Mifsud Bonnici</td>
<td>University of Groningen (The Netherlands)</td>
</tr>
<tr>
<td>Mr Jean Louis Pierquin</td>
<td>Pôle MIPI (France)</td>
</tr>
<tr>
<td>Dr Olli Pitkänen</td>
<td>Helsinki Institute for Information Technology – HIIT (Finland)</td>
</tr>
</tbody>
</table>

4.4. Term of appointment

The EAB will be established by January 2012 and the members of the EAB will be appointed until the end of the EXPERIMEDIA project, September 2014.

4.5. Chair

One EAB member will be responsible for chairing the meetings. This Ethical Advisory Board Chair will be approved by the Project Officer of the EXPERIMEDIA Project.

4.6. Meeting procedures

The EAB will convene every six months, for the evaluation open calls and after the design phase of each experimental phase. In addition, the EAB will have a mechanism for review of urgent or short-notice cases.

The EAB members join the meetings in person. However, in exceptional situations, members could join the meetings via teleconference.

4.7. Reporting

Prior to the commencement of an experiment work package an ethical review will be conducted by the Ethics Advisory Board. For driving experiments (WP4.1, WP4.2 and WP4.3) an ethical
review will be conducted within the first 6 months of the project prior to the scheduled start
time. For open call experiments, an ethical review will be conducted as part of the proposal
evaluation process.

Every six months, the EAB must submit a report of its activities:

- Driving Experiments Ethics Review Report of the three driving experiments within
  EXPERIMEDIA [est.: month 6]
- 1st Open Call Ethics Review Report [est.: month 12]
- 2nd Open Call Ethics Review Report [est.: month 24]
- Final Ethics Review Report [est.: month 36]

For the open call experiments, the Ethical Review Reports will be submitted to the European
Commission as part of the EXPERIMEDIA deliverables prior to the commencement of the
new experiments.

4.8. Conflict-of-interest disclosure

Board members should perform their functions in good faith, honestly and impartially. Members
must declare conflicts of interest prior to the discussion of a specific experiment. A conflict of
interest refers to situations in which personal, occupational or financial considerations may affect
or appear to affect the objectivity or fairness of decisions. Members must declare potential
conflicts to the chair and must absent themselves from the discussion.

4.9. Confidentiality and non-disclosure agreement

Each Board member must sign a confidentiality and non-disclosure agreement at the time of
appointment indicating their agreement to maintain the confidentiality of all materials during and
after their term on the Ethics Advisory Board.

4.10. Remuneration

The travel and meeting logistics costs will be covered by the EXPERIMEDIA project.

4.11. Amendment to terms of reference

The EXPERIMEDIA consortium may amend the terms of reference at any time.
5. Data Protection Board - Terms of Reference

In addition to the EAB, a Data Protection Board (DPB) will be created.

5.1. Membership
The DPB will be composed of six permanent members:

Data Protection Controller (Jos Dumortier, K.U.Leuven)

Activity leaders:

- Activity 1 leader (Stephen Phillips, IT Innovation)
- Activity 2 leader (Angelos Yannopoulos, NTUA)
- Activity 3 leader (David Salama, ATOS)
- Activity 4 leader (Wolfgang Halb, Joanneum Research)
- Activity 5 leader (Eric Seulliet, La Fabrique du Futur)

If necessary, for instance if a topic-specific exchange of ideas, or an in-depth summary of work in progress is required, local operational staff and data guardians will be invited to the meetings of the DPB.

5.2. Chair
The Data Protection Controller will be the chair of the DPB.

5.3. Objectives
The DPB is responsible for ensuring that EXPERIMEDIA is compliant with data protection requirements and to ensure that the technical partners develop a system that considers privacy and data protection (based on the ethical principles for EXPERIMEDIA – see below). A key objective is to comply with the principle of proportionality. This principle requires that the measure taken should be appropriate and necessary to achieve the goal pursued. The DPB will consider a three-part test: the ‘suitability’ test, which defines whether the measure is reasonably likely to achieve its objectives; the ‘necessity’ test, which evaluates whether there are other less restrictive means capable of producing the same result; and the proportionality test stricto sensu, which consists of a weighing of interests with which the consequences on fundamental rights are assessed against the importance of the objective pursued.

5.4. Meeting procedures
The DPB will meet in person during the General Assembly meetings, while the other meetings will be held via teleconference. During these meetings the open calls will be evaluated, the design phase of each experiment will be discussed status updates will be given, etc. The DPB will include a mechanism for review of urgent or short-notice cases.
6. Ethical oversight principles for the EAB and DPB

EXPERIMEDIA will implement ethical oversight measures for each experiment to clarify the conditions under which social and networked media research is acceptable covering informed consent, deception, debriefing, right to withdraw, and confidentiality in accordance with personal data legislation.

6.1. General
EXPERIMEDIA will consider the ethical implications and consequences for the participants in their research. All experiments will be considered from the standpoint of all participants; foreseeable threats to their well-being, health, values or dignity will be eliminated. EXPERIMEDIA involves participants from multi-cultural and multi-ethnic societies and where experiments involve individuals of different ages, gender and social background.

6.2. Informed consent
EXPERIMEDIA will inform all participants of the research objectives and all aspects of the research that might reasonably be expected to influence willingness to participate. EXPERIMEDIA will explain all other aspects of the research about which the participants enquire. This will be done before participants are asked to join an experiment so their decision will constitute informed consent. EXPERIMEDIA will avoid situations where participants feel pressured to take part in an experiment. Direct payments are not expected for participation but other incentive mechanisms may be designed to encourage participation. Such incentive mechanisms will not be designed to induce participants to risk harm beyond that which they would hazard in normal life. EXPERIMEDIA is not expecting longitudinal research as experiments are expected to be conducted for less than 12 months, and not repeated, however, where necessary consent will be obtained on more than one occasion.

6.3. Deception
EXPERIMEDIA will never intentionally deceive, mislead or withhold information from participants over the purpose and general nature of the investigation.

6.4. Data collection
EXPERIMEDIA will collect personal data about participants during experiments. EXPERIMEDIA will provide participants with any information to complete their understanding of the nature of the research at the end of an experiment. EXPERIMEDIA will discuss with the participants their experience in order to monitor any unforeseen negative effects or misconceptions.

EXPERIMEDIA will adopt a principle of data minimisation: only the necessary information will be collected and processed and the information will be stored only for as long as is necessary.

EXPERIMEDIA will deploy anonymisation or pseudonymisation techniques to remove the ability to identify individuals where possible. EXPERIMEDIA cannot just use fully anonymous
EXPERIMEDIA will need to protect two types of data. Firstly, service data including user queries which are often trackable (correlatable with an individual) and even traceable (to a specific individual). Secondly, sensor data collected from users to provide services (e.g. images/voices of people).

EXPERIMEDIA will only store user profiles when the consent of the users is acquired and only for the purpose and lifetime of experiments. There will be no commercial exploitation of user profiles within the lifetime of the project.

EXPERIMEDIA is aware of advanced technical measures necessary to minimise these risks to privacy:

- use of secure data storage, encrypted transfer, controlled and auditable access for different classes of data distributed over the same channel;
- obscuring/removing user identities at source (e.g. in the user’s own smartphone or home network, depending on application) to prevent direct user tracing;
- obscuring even the user id as much as possible depending on application needs to prevent user tracking
  - e.g. using peer-to-peer data aggregation networks where individual responses are not needed
  - e.g. using ID obscuration unless user tracking is needed (e.g. for billing or to allow consistent user interactions)
- obscuring location through indirect/delayed routing to prevent individual localisation as much as possible and limit user tracking through correlation of depersonalised data based on its location.

EXPERIMEDIA is not expecting direct commercial exploitation of personal data within the lifetime of the project. If the event does occur and the outputs of the project are used as the basis of commercial products, services or business applications, the data will be dealt with in accordance with the “Consumer protection from Unfair Trading Regulations and Business Protection from Misleading Business Practice Regulations (together these implement Directive 2005/29/EC of the European Parliament and of the Council concerning unfair business-to-consumer commercial practices).

6.5. Withdrawal from the investigation
EXPERIMEDIA will make plain to participants their right to withdraw from the research at any time, irrespective of whether or not payment or other inducement has been offered. In the light of experience of the experiment, or as a result of debriefing, the participant will have the right to withdraw retrospectively any consent given, and to require that their own data be destroyed.
6.6. **Observational research**

EXPERIMEDIA is expected to include observational research and therefore will respect the privacy and well-being of the individuals studied. EXPERIMEDIA includes two public venues (Schladming and FHW) which may include individuals being observed that have not given consent. This will only be done in situations where those observed would expect to be observed and possibly recorded by strangers. For example, an individual in a public venue might expect to be filmed or photographed, but not to have their conversation recorded. Experiments in that venue would be permitted if they involve video capture, but not if they involve sound recording of individual spectators. Additionally, particular account will be taken of local cultural values and the possibility of intruding upon the privacy of individuals who, even while in a normally public space, may believe they are unobserved.

6.7. **Data Protection Regulation**

EXPERIMEDIA must be developed and operated in full consideration of data protection principles and must satisfy data protection requirements in accordance with EU Directives and their national implementations. EXPERIMEDIA has three physical testbeds (Schladming, CAR and FHW) and online communities (3D Innovation Living Lab, Facebook, etc), each with distinct privacy concerns and each operated in different legal jurisdictions. In understanding, tracking and modelling behaviours of users in online and real world communities, it is likely that personal data of some description will be captured and processed. The data will be made up of that collected anyway as part of normal operations, plus additional data required by experiments.

All personal data will be captured and processed according to the applicable data protection provisions, such as Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data, including Article 29 Working Party 8/2010 opinion, and Directive 2002/58 on Privacy and Electronic Communications) and the national data protection legislation that may be applicable.

6.8. **Consortium Partner Responsibility**

All consortium partners share responsibility for the ethical treatment of research participants with their collaborators, assistants, students and employees. A researcher who believes that another researcher may be conducting research that is not in accordance with the principles above should encourage that researcher to re-evaluate the research.
7. Definitions

Data Protection

The ability to protect information that relates to an identified or identifiable natural person ("data subject") from disclosure to unauthorized recipients in accordance with an individual’s fundamental right to privacy as defined by the European Convention on Human Rights and the European Charter of Fundamental Rights.

Profiling

The collection of personal data about a data subject.

Tracking

The monitoring of an individual’s behaviour over time.

Location based applications

A system that uses geographical location to deliver information or entertainment, typically to mobile devices.

Processing of personal data

Any operation or set of operations which is performed upon personal data, whether or not by automatic means, such as collection, recording, organization, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, blocking, erasure or destruction.

Social and ethical implications of Future Internet developments, particularly involving large-scale usage

The impact of technology research in EXPERIMEDIA on individuals and the communities they are part of.

Volunteers

Individuals participating in experiments.

Consent

Authorisation from volunteers for participation in experiments.
8. Conclusion

As EXPERIMEDIA will be conducting research with human participants and is, in particular, interested in human behaviour and experience when interacting with the technology of the future internet, the project must be very clear and careful with ethics and data protection.

In this document we have set out the various roles associated with ethics and data protection and their responsibilities: the ethical issues coordinator, a data protection coordinator along with an Ethics Advisory Board (EAB) and Data Protection Board (DPB). We have described the terms of reference for these boards and their initial membership composition, mandate, operating procedures and meeting procedures. Furthermore, this deliverable contains an overview of the ethical oversight principles that should be taken into account by the EAB and DPB for each experiment.