



# The Collective Experience of Empathic Data Systems

ICT-258749

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## Deliverable 10.2

### Project ethical guidelines

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# 1 Executive Summary

This privacy policy regulates the ethics in the treatment of human participants, especially in the collection, storage, treatment and dissemination of personal data during the life of the CEEDs project and after its end, and specific provisions for prototype design.

The present policy follows the ethics code elaborated by associations of professionals working with humans or with technologies such as the American Psychological Association<sup>1</sup>, The British Psychological Society<sup>2</sup>, and the Association for Computing Machinery<sup>3</sup>. It also complies with the EU Data protection Law (the Directive 95/46/EC<sup>4</sup> and the Directive 2002/58/EC on privacy and electronic communications<sup>5</sup>) and with CEEDS Grant Agreement (Article 7.1 Special clause n. 15). For aspects that are not specified in this document, partners are referred to such professional and international regulations.

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<sup>1</sup> <http://www.apa.org/ethics/code/index.aspx>

<sup>2</sup> [http://www.bps.org.uk/document-download-area/document-download\\$.cfm?file\\_uid=E6917759-9799-434A-F313-9C35698E1864&ext=pdf](http://www.bps.org.uk/document-download-area/document-download$.cfm?file_uid=E6917759-9799-434A-F313-9C35698E1864&ext=pdf)

<sup>3</sup> <http://www.acm.org/about/code-of-ethics>

<sup>4</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=DD:13:15:31995L0046:LV:PDF>

<sup>5</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2002:201:0037:0047:EN:PDF>

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## 2 Risks

### 2.1 Data categories

As declared in the technical annex, CEEDs works with human data, which are collected in the trials, in the laboratory studies, and in various dissemination activities. This includes personal data and, occasionally, sensitive data. *Personal data* means any information relating to an identified or identifiable natural person ('data subject'); an identifiable person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his/her physical, physiological, mental, economic, cultural or social identity (95/46/EC, Art. 2). *Sensitive data* is any information that might result in loss of an advantage or level of security if disclosed to others who might have low or unknown trustability or undesirable intentions<sup>6</sup>. CEEDs also uses *copyrighted or confidential* data resulting from activities external to the project activity.

### 2.2 Areas of risk

The usage of the data listed in 2.1 along with the specific nature of the applications and technologies to be developed in the project (working with implicit knowledge) make them potentially able to result in the infringement of privacy rights and in other ethic risks. To better specify the essence of these risks and then take effective measures to reduce them, CEEDs consortium has taken an internal survey. The following areas of risk have emerged as relevant to the project (within brackets, the number of partners who have considered a risk as likely):

- User's identification based on collected data (8 respondents) (Ohm, 2010)
- Permanence of personal/ sensitive data after project conclusion (6 respondents) (El Emam, Neri, & Jonker, 2007)
- Access to personal information when users don't realize it (5 respondents) (Kuzu, 2009; Britz, 1996; Moor, 2010)
- Public, unrestricted access to collected data (5 respondents)
- Production of code or software that can be misused by third parties (4 respondents) (Britz, 1996)
- Public disclosure of confidential information about an individual (4 respondents) (Myers, 1996)
- Misinterpretation of data disregarding their original meaning when produced (3 respondents) (Britz, 1996)
- Profiling (by merging databases, by data-mining) and attribution of new property to the individual derived from implicit patterns (2 respondents) (Tavani, 2004; Tavani 1999; van Wel and Royakkers 2004)]

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<sup>6</sup> [http://en.wikipedia.org/wiki/Information\\_sensitivity](http://en.wikipedia.org/wiki/Information_sensitivity)

- Disguised data collection devices that are difficult to recognize (ambient interfaces, wearables, ...) (1 respondent)
- Hidden persuasive strategies (1 respondent) (Naylor, 1958)
- Anticipable persistent and non-trivial effects in research participants (1 respondent) (Birgegard, 2008)

## 3 Provisions to reduce privacy risks

The protection from risks listed in § 2 requires special practices when collecting, storing, treating and disseminating data, and appropriate solutions in the construction of data collection tools and of the CEEDs prototypes. The general guidelines taken in the consortium to this respect are listed in this Section. Regulation of copyright and intellectual properties right is dealt with in the CEEDs Consortium Agreement.

### 3.1 Responsibilities

- 3.1.1 Each CEEDs researcher is responsible for informing his/her *collaborators* about the present policy.
- 3.1.2 Each partner is responsible for obtaining ethical *approval* for research s/he leads (or even contributes to in case this is needed by his/her institution).
- 3.1.3 Each member of the Consortium is responsible for the compliance of his/her own deeds with the present policy and annexed documents, and for highlighting specific issues to the PCC if they emerge, including any conflict with their own institutions privacy policy. In addition, each partner specifies in the list below who is the *person* responsible for data protection. These persons are responsible for the compliance with this policy in their unit. Any modification in this list during the project should be communicated to the Coordinator.

| PARTNER N. | PARTNER'S NAME                                                 | PERSON IN CHARGE OF DATA PROTECTION |
|------------|----------------------------------------------------------------|-------------------------------------|
| 1          | GOLDSMITHS' COLLEGE                                            | Jane Lessiter                       |
| 2          | UNIVERSITAT POMPEU FABRA                                       | Paul Verschure                      |
| 3          | UNIVERSITY OF SUSSEX                                           | Anil Seth                           |
| 4          | CENTRE FOR RESEARCH AND TECHNOLOGY HELLAS                      | Petros Daras                        |
| 5          | EBERHARD KARLS UNIVERSITAET TUEBINGEN                          | Andrea Caria                        |
| 6          | UNIVERSITAET AUGSBURG                                          | Ulrich M. Gassne                    |
| 7          | UNIVERSITY OF TEESSIDE                                         | Andrew Rawnsley                     |
| 8          | UNIVERSITÀ DEGLI STUDI DI PADOVA                               | Anna Spagnolli                      |
| 9          | MAX PLANCK GESELLSCHAFT ZUR FOERDERUNG DER WISSENSCHAFTEN E.V. | Jürgen Jost                         |
| 10         | ECOLE NORMALE SUPERIEURE                                       | Sid Kouider                         |
| 11         | BUDAPESTI MUSZAKI ES GAZDASAGTUDOMANYI EGYETEM                 | Barnabas Takacs                     |
| 12         | UNIVERSITAT POLITECNICA DE CATALUNYA                           | Alberto Sanfeliu                    |
| 13         | UNIVERSITÀ DI PISA                                             | Danilo De Rossi                     |
| 15         | ELECTROLUX ITALIA S.P.A.                                       | Claudio Cenedese                    |

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|----|---------------------|------------------|
| 16 | UNIVERSITEIT LEIDEN | Roswitha Manning |
| 18 | HELSINGIN YLIOPISTO | Eve Hoggan       |

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- 3.1.4 *After the end of the project*, the people listed in §3.1.3 remain responsible for data protection or – in case they leave their institution – for the appropriate transfer of this responsibility to protect the data confidentiality.

## 3.2 Informed Consent

- 3.2.1 Personal data is collected only after the owner of this data signs an informed consent which is read and signed before the data collection and includes descriptions of the:
- study goals, funding agency, institution performing the data collection, usage of the data collected (e.g., research, dissemination material, ...);
  - data collection techniques employed involving the participant, of the general topic of the data collected and of the length of the data collection procedure;
  - kind of people who can access the data and way in which they are processed and disseminated;
  - mutual commitment to confidentiality; and
  - benefits, risks (if any) in participating, right to refuse/end participation, possibility to ask questions prior or after the research, debriefing modality and contact info of a person in the research team.
- 3.2.2 The consent form is written so as to be *comprehensible* to participants, without jargon or technicalities.
- 3.2.3 Personal data of people *underage* (i.e., under 18 years) is used with the additional consent of the persons having their custody (e.g., parents).
- 3.2.4 Users are alerted if content sent through the system is *monitored* or made public.
- 3.2.5 Data that is *not needed* for the correct functioning of the system or for the field/lab studies is not collected.

If the data collection takes place without directly interacting with the user i.e. in public places or by using archives, then the informed consent must be obtained from the institution where this data is stored if these places already make clear to the users that their data can be given to third parties. Otherwise, permission must be also obtained from each user.

The consent can be asked about the whole data collection and treatment or split into consents to each specific aspect (e.g. separating data collection from dissemination) so that the risk of excluding a certain participant altogether is reduced.

## 3.3 Trial/demos

The trial/demos involve the same responsibilities illustrated above. In addition, a specific agreement with the participants must define the following aspects:

- 3.3.1 Responsibilities for *damage* caused to participants by CEEDs system are defined before trials start; presence or absence of *compensation* to participants is made explicit from the start as well as the responsibility for *installation* and *removal*



- 3.3.2 *Temporary 'opting out'* from the service by trial participants is allowed and monitored; its consequences are explained to participants beforehand.
- 3.3.3 Definition of *Terms of usage* of the tools, tool set up, users' training and maintenance are responsibility of the Consortium in ways to be specified.

## 3.4 Design and development

- 3.4.1 CEEDs prototypes must comply with all *safety* standards.
- 3.4.2 The development cycle includes the identification of privacy risks and the implementation of measures to prevent these risks in accordance with the present document provisions.
- 3.4.3 Access to data is regulated.
- 3.4.4 Technical measures to protect personal data against accidental or unlawful destruction or accidental loss, alteration, unauthorized disclosure or access are taken.
- 3.4.5 Users' concerns that might arise during studies, demos or trials must be adequately addressed.
- 3.4.6 Content of the CEEDs applications and their purpose is neither offensive nor discriminatory.

## 3.5 Data protection

- 3.5.1 Partners in the project commit themselves not to *misuse* the data collected during and after the project. In particular they commit not to use them against participants, nor to sell this information to third parties, and to use the data only in anonymous format unless specifically agreed with participants
- 3.5.2 Data collected with any tool is *anonymized*; this means that participants have to be identified only with a code. The association between participants' identity and codes has to be kept in a different file, securely stored. This file, allowing to associate data to the identity of their owners, must be destroyed when CEEDs project ends. Any data that cannot completely be separated from the identity of the owner (e.g. video recordings) is stored in locked rooms and publicly displayed only if-and according to what is- expressly allowed in the informed consent.
- 3.5.3 Identity information and data are *accessible* only to CEEDs researchers for purposeful reasons connected and compatible with CEEDs goals, who have permission from the people storing the data. By "CEEDs researchers" we mean the people listed in the technical Annex and, through them, the people collaborating with them in the project.

## 4 Adoption

The Consortium knows, approves and adopts this document during the PCC meeting held on 12-13 September 2011 in Barcelona and commits to

- make it continuously *available* from the CEEDs websites (public and internal)
- *inform any current and future collaborator* within the CEEDs project of the commitments taken with this document

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