SOME REFERENCE TERMS FOR A HUMAN RESEARCH ETHICS REVIEW

Key Concepts
References

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Key Concepts

Research involving human participants
Ethics & types
Ethics: unavoidable & pervasive
Institutional tools
Informed consent
On data gathering
Research involving human participants

• **What does “research involving human participants” mean?**
  - There is some intervention or interaction with another person for the purpose of gathering information, OR
  - Information is recorded by the researcher in such a way that a person can be identified directly or indirectly with it

• **Notes:**
  - Spontaneous conversations, if gathered in a publicly accessible venue, is not (regarded as) human *subjects* research
  - The delimitation is fuzzy
Ethics are widely defined as the standards of proper conduct.

You might come across different types of ethics:
- Personal ethics: your own principles of right and wrong behavior
- Corporate ethics: obligations promulgated by the organizations that employ a researcher
- Professional ethics: set of standards of conduct adopted by professionals (written under the label “code of ethics”)
- Research ethics: forms of behavior that have normative expectations for researchers

We deal with the latter two.

Ethics, unavoidable & pervasive

• Ethics in research involving humans **should be** UNAVOIDABLE
• Ethics in research involving humans is PERVERSIVE
  – From writing up the project, conducting the research to publication
• Fulfilling ethical obligations in research is not only **good** ethics but also **good** science
CIREP created by UPF to:

- Improve ethical standards
- Advice researchers / lecturers on ethical issues and data protection
- Liaise with CEIC Parc de Salut Mar

Documentation:

- Ethical issues checklist (compulsory for everybody)
- If issues: Summary (300 words) + Procedure (5000 words) + Informed consent
Informed consent

• “All international declarations stipulate that, prior to consent, each participant in a research project should be clearly informed of its goals, its possible adverse events, and the possibility to refuse to enter or to retract at any time with no consequences” (Ethics for Researchers, FP7-EU, 2007)

• Informed consent documents generally ask the subject to attest that he or she has been informed about:
  – the nature of the study, his or her participation in it, the potential risks or lack thereof,
  – that s/he is free to discontinue participation at any time with no penalty,
  – and other standard warnings as apply in the respective instance
Informed consent: some reflections

• **Who should consent?**
  – Imagine your participants have some type of cognitive impairment. In this case, researchers seek consent from their relatives, doctors...

• **How to inform?**
  – Often, face-to-face is not possible (online, for example)
  – You might think: ok, I will write up the “Terms & Conditions” page, which will be the first page to appear in your online survey. Do you think that (or know of) people read these T&C?

• **What and how to write it?**
  – The wording becomes very important: “use the information you provide me within this study for my research” – what information? What does research mean – this study, another, papers, presentations...?
Gathering, using and storing “human data”

- Human Data handling is very important, even more when Big Data is fashionable
- LEY NICA 15/1999, de 13 de diciembre, de Protección de Datos de Carácter Personal
- Artículo 4.2. “Los datos de carácter personal objeto de tratamiento no podrán usarse para finalidades incompatibles con aquellas para las que los datos hubieran sido recogidos”.
- Artículo 4.5. “Los datos de carácter personal serán cancelados cuando hayan dejado de ser necesarios o pertinentes para la finalidad para la cual hubieran sido recabados o registrados”
- Artículo 5. Derecho de información en la recogida de datos
- Artículo 6.1. “El tratamiento de los datos de carácter personal requerirá el consentimiento inequívoco del afectado, salvo que la ley disponga otra cosa”
• Artículo 9.1. “El responsable del fichero, y, en su caso, el encargado del tratamiento deberán adoptar las medidas de índole técnica y organizativas necesarias que garanticen la seguridad de los datos de carácter personal y eviten su alteración, pérdida, tratamiento o acceso no autorizado, habida cuenta del estado de la tecnología, la naturaleza de los datos almacenados y los riesgos a que están expuestos, ya provengan de la acción humana o del medio físico o natural”.

• Artículo 12.1. “Una vez cumplida la prestación contractual, los datos de carácter personal deberán ser destruidos o devueltos al responsable del tratamiento, al igual que cualquier soporte o documentos en que conste algún dato de carácter personal objeto del tratamiento”
References

Professional ethical codes
Legislation
Further reading
Professional ethics

- ACM Code of Ethics and Professional Conduct
  - [http://www.acm.org/about/code-of-ethics](http://www.acm.org/about/code-of-ethics)
- British Computer Society Code of Conduct
  - [http://www.bcs.org/category/6030](http://www.bcs.org/category/6030)
- Code of Ethics and Conduct British Psychology Society
- Codi Deontològic del Col·legi oficial d'Enginyeria en Informàtica de Catalunya
• Ethics is sometimes regulated by law!
• International Compilation of Human Research Standards
  – Over 1,000 laws, regulations, and guidelines that govern human subjects research in 103 countries, as well as the standards from a number of international and regional organizations (DOC)
• In Spain


5. Organic Law 15/1999 of December 13 on the Protection of Personal Data: [https://www.agpd.es/upload/Ley%20Org%E1nica%201999_ingles.pdf](https://www.agpd.es/upload/Ley%20Org%E1nica%201999_ingles.pdf)


... Note: Organizations might have their own local regulations
References & Further reading


• *European Textbook on Ethics in Research*, 2010


ACM, IEEE, Ethics and Information Technology journal...