Chapter 17
Ethical Issues for User Involvement in Technological Research Projects:
Directives and Recommendations

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ABSTRACT

In recent years, it has become common for users to participate in the development of new technologies for health and quality of life. This development requires ethical issues to be taken into account. In this chapter, the researchers review the important recommendations and directives both worldwide and in European legislation in order to guide technological researchers. All research with human participants that poses any risk to them must be supervised by an external multidisciplinary entity. In addition, the participants must decide whether or not they want to participate, having been provided with all the information about the experiments and the risks of taking part. The privacy of the participants' personal data is another important issue.

INTRODUCTION

User involvement is an active process that involves users[1] or stakeholders[2] taking part in different phases of a project. Users should identify their preferences in order to develop new products that meet their needs with useful and easy-to-use-designs which will be successfully introduced into the market. The involvement of users and stakeholders in research projects requires the ethical and legal issues related to human participation in research to be taken into consideration to avoid bad practices. A number of cases can be found where research projects related to the patients' health have exceeded ethical boundaries and today we identify these as atrocities. Following these cases, some organizations regulated the human participation in research studies in order

to ensure the physical and psychological safety of the participants over the research objectives and to ensure that their participation is voluntary, as it will be detailed further in this chapter.

This study focuses on the ethical implications related to the involvement of users in research studies to improve the design and development of new products, including technological devices for health and quality of life.

Some professions, such as journalism, psychology or medicine, adhere to a code of practice (European Parliament, 1993; Psychologist Official Colleges, 2010; Medical Colleges of Spain, 1999). These codes consist of criteria, rules and values that should be applied by the corresponding professionals. Codes of practice address ethical aspects and are increasingly common in new disciplines that involve working with human beings or require their participation. Moreover, in some professions the codes apply to difficult issues in professional life and sanctions are even included for non-compliant professionals. In the case of Spain, for example, some professions are regulated by law, such as the health-related professions (Spanish Government, 2003b) and the law (Ministry of Justice, 2001) where a reference to the code of practice can be found. However, in other cases, such as architecture and engineering, which have a corresponding law (Spanish Government, 1992), there is no reference to a code of practice, and in these professions involvement of human beings is also needed. The practitioners of these disciplines who conduct experiments with human participation must also take into account the applicable ethical issues and it is hard to find some guidelines for that. In some cases the ethical considerations can be subjective and dependent on other factors, such as culture, personal values and principles. With the aim of making an evaluation as objective as possible, there are some recommendations, rules and laws that every researcher conducting

research with human participants should know. Different literature can be found on these ethical issues, which makes it difficult to analyze them, and some researchers in different disciplines do not know these ethical principles.

The National Society for Professional Engineering (NSPE) in the USA approved a Code of Ethics for Engineers (National Society of Professional Engineers, 2007), but, as Michelfelder and Jones (2011) explained, this and other similar codes for engineers do not talk "in terms of the safety, health, and welfare of the public".

Motivated by these problems, in this study we reviewed the existing and most important rules, recommendations and laws, focusing in particular on those in European legislation.

This work has been divided into five more sections:

1. **Bioethics Section:** Explaining the main principles concerning ethical issues related to the treatment of human subjects.
2. **Bioethics, Rules, and Legislation:** Where the different rules concerning health-related technological research are discussed.
3. **Personal Data Protection:** Which is directly related to the above ethical issues, because the treatment of the personal data of the participants in the research must be appropriate.
4. **Conclusions and Recommendations**
5. **Future Research Directions**

BIOETHICS

The term "Bioethics" was first used in the 1970s (Potter, 1970). This word is composed of the two Greek words *bios* and *ethos*, which mean *life* and *science of customs* or *ethics* (Gracia, 2002). Bioethics examines the ethical issues related to life,

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