

ETHICAL FRAMEWORK

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OUTLINE OF THE PRESENTATION

- Why should we address ethical and privacy issues in European projects?
- Common ethical and privacy topics in European projects
- Ethics in the VUMS cluster

WHY SHOULD WE ADDRESS ETHICAL AND PRIVACY ISSUES IN THE EUROPEAN PROJECTS?

- Charter of Fundamental Rights of the European Union: dignity, freedom, equality, solidarity, citizens' rights and justice
- All elderly people should be provided with the same opportunities of access to ICTs regardless of their:
 - Age group: elderly people and very old people – over 85 years of age
 - Gender:
 - different roles and attitudes towards technology.
 - equal number of males and females participating in the user trials
 - study of the different impact that the project could have on the two genders
 - Language and images
 - Cultures: People from different cultures may have different needs, opinions, history of use with technology,

GENERAL ETHICAL FRAMEWORK: THE 4 PRINCIPLE APPROACH

1. Non-maleficence. The study should not harm the participant, or put him or her under unacceptable risk (this includes risks to privacy).

2. Beneficence. The study should benefit the participant

3. Justice. The study and general operation of the device should take into account the legitimate interests of third parties, and not incorporate or promote any bias based on gender, culture, nationality, or other sources of social prejudice (this includes fair selection of the subjects for the user trials).

4. Respect for autonomy. Participation in the study should be based on a process of informed consent, and the participants' right to control his or her personal information will be respected at all times (this includes issues of confidentiality and data security).

PEOPLE CAN BELONG TO MORE THAN ONE EXCLUDED GROUP

	Marginalised Young People	Cultural Minorities	Elderly Persons	People with Disability	Online Government Services	EU citizens 0-15	EU citizens 16-18	EU citizens 19-65	EU citizens 65+
Marginalised Young People	✓			✓	✓	✓	✓		
Cultural Minorities	✓	✓	✓	✓	✓	✓	✓	✓	✓
Elderly Persons		✓	✓	✓	✓				✓
People with Disability	✓	✓	✓	✓	✓	✓	✓	✓	✓
Online Government Services	✓	✓	✓	✓	✓	✓	✓	✓	✓
EU citizens 0-15	✓	✓		✓		✓			
EU citizens 16-18	✓	✓		✓	✓		✓		
EU citizens 19-65		✓		✓	✓			✓	
EU citizens 65+		✓	✓	✓	✓				✓

PRIVACY

- Privacy problems exist whenever identifiable data relating to a person or persons are collected and stored, in digital form or otherwise
- The challenge in data privacy is to share data while protecting personal identity from the information gathered

- Privacy plays a role at different levels:
 - Hints to or specific personal information of any participant in publications
 - It should be forbidden to reveal the identity of participants in research deliberately or inadvertently, without the express permission of the participants.
 - Dissemination of data among partners
 - Offer restricted access to privacy sensitive information within the organization of the partner.
 - Protection of privacy within the organization of volunteers (employers, etc.) throughout the whole process for instance in communications, data exchange, presentation of findings, etc.

- The European Directive on the protection of personal data contains a number of key principles which must be complied with. Anyone processing personal data must comply with the eight enforceable principles of good practice. They say that data must be:
 1. Fairly and lawfully processed.
 2. Processed for limited purposes.
 3. Adequate, relevant and not excessive.
 4. Accurate.
 5. Not kept longer than necessary.
 6. Processed in accordance with the data subject's rights.
 7. Secure.
 8. Not transferred to countries without adequate protection.

COMMON ETHICAL AND PRIVACY TOPICS IN EUROPEAN PROJECTS

- **Purpose of the Data Protection Plan:**
 - All members of the research team with access to the data are contractually obliged to follow all aspects of the Data Protection Plan.
 - The fundamental goal of the protections outlined in this plan is to prevent persons who are not signatories to the Restricted Data Use Agreement or the Supplemental Agreement with Research Staff from gaining access to the data.

- **Informed consent:** Process by which a participant will be fully informed about the research
 - Purpose of the study
 - Study participants and procedures
 - Risks and Disadvantages
 - Benefits
 - Privacy and Confidentiality
 - Voluntary Participation/Withdrawal
 - Questions
 - Confirmation

- **Process of encoding or anonymization:**
Information should be anonymized so that individual identities cannot be revealed.
- **Security measures for storage and handling.**
stored in a locked server, and all identification data will be stored separately

ETHICS IN THE VUMS CLUSTER

- Aim:
 - To ensure compliance with ethical issues during the whole project
 - To develop an Ethical Guideline or Manual about the general ethical approach to be followed throughout the projects. In this Manual a consensus about the following issues will be reached:
 - How to save and exchange personal data between partners of the same project
 - How long the personal information will be saved after completing the projects
 - Which photographs or videos will be used in congresses and dissemination events (either to provide the participants with a different consent form for this issue or recruit volunteers)