Training and cooperation activity (TCA) – Data protection and the ethics of data collection in Erasmus + projects

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- General ethics framework in EU programmes

- What can Erasmus + learn from other programmes such as HORIZON Europe

- What activities can include processing of personal data and how project promoters can deal with them?

General ethics framework in EU programmes

Ethics framework

- Some EU programmes (e.g. HORIZON Europe, Digital Europe) require ethics compliance, i.e. the identification and management of potential ethical issues that may arise in a project :

    - to ensure compliance with applicable international, EU and national law

- Horizon Europe (Article 19 REGULATION (EU) 2021/695 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL establishing „Horizon Europe")

- Compliance with ethical principles is of crucial importance for all scientific fields (not just the life sciences).

- All proposals that are eligible for funding are subject to an ethics review - compliance with ethical principles is monitored during project implementation

Ethics issues to be examined

- Human embryonic stem cells (hESCs) and human embryos (hEs) .
- **Humans**
- Human cells or tissues
- **Personal data**
- Animals
- Non-EU countries
- Environment, health and safety
- **Artificial intelligence**
- Other ethics issues
- Crosscutting issue: potential misuse of results

Ethical evaluation and monitoring process in HORIZON Europe

- ▶ Concerns proposals that are included in the shortlist (main and reserve list)

- ▶ Follows a risk-based approach - focus on serious and complex ethical issues

- ▶ Proposal phase: Screening of proposals and their self-assessment (evaluation of issues included in the self-assessment and/or identification of new ethical issues). Two main outcomes of the evaluation:

  - ▶ No serious or complex problems -> Full clearance or conditional clearance (e.g. appointment of an ethics advisor, ethics board if necessary)

  - ▶ Serious or complex problems -> ethics assessment with clearance, conditional clearance or no clearance

Ethical evaluation and monitoring process in HORIZON Europe

Project implementation:

- If an ethics assessment has been carried out: specific requirements prior to the signing of the grant agreement and/or certain deliverables required as part of project reporting and monitoring

- If no ethics assessment: no specific requirements, but

    - Evaluation report as a reminder to the beneficiaries of the declarations they have made in the application

    - Possible ethics checks/reviews or appointment of an independent ethics advisor/ethics advisory board

What Erasmus + can learn from other programmes such as HORIZON Europe

Two main concepts

▶ Ethics by design

　　▶ Include ethical considerations and principles in the development of a project, product etc.

▶ Data protection by design

　　▶ Embed measures that can safeguard privacy and data protection at the early phases of a project design and not only later

Address an issue at the development phase than try to fix it later in the process

Proactivity and self-assessment

Even if the procedure in Erasmus + does not foresee such a process you could/should:

▶ Be proactive and identify issues related to processing of data

▶ Perform at project conceptualisation and proposal writing phase a self-assessment of what issues could possibly arise in the project's different elements, e.g.

    ▶ Objectives of the project

    ▶ The methodology

    ▶ The impact of the activities

▶ Discuss with your partners about your ideas and concerns and do not wait until the implementation of the project

Some important aspects (examples) to examine if you want to involve individuals

- Justification of the participation of individuals
- Information of the individuals about their participation – informed consent
- The profiles of participants you plan to involve (e.g. adults, minors, refugees etc)
- The practices you will use to collect data from your participants and how to ensure the protection of their privacy

Some important aspects (examples) to examine the personal data you may need to process

- Use of previously collected data – secondary use of data
- Collection of 'special categories" of data (e.g. political opinions, ethnic origin etc.) or data of minors and vulnerable people
- Safe storage of data
- Data to be used, imported from or transferred outside the EU
- Retention periods and deletion of data

Some important principles(examples) in working with artificial intelligence

► Any possible activities involving artificial intelligence need to respect personal data protection and privacy principles

► Ensure that people are aware they are interacting with an AI system and are informed about its abilities, limitations, risks and benefits

► AI systems should be developed with mechanisms that enable human oversight, transparency and auditability

Artificial intelligence act – A risk-based approach

- **Minimal risk:** Most of the AI systems used could fall into this category (e.g. AI enabled spam filters)

- High-risk: AI systems that could create an adverse impact on people's safety or fundamental rights

- Unacceptable risk: A threat to the citizens

- **Specific transparency risk:** Humans to be notified that they interact with AI

Definitions of risks and methodologies to identify them included in the act

Important aspects (examples) to consider when involving humans

Data protection in project implementation

Data protection in project implementation

- Data protection in project implementation can be at different levels:
    - The Relevance and the innovation of the project (project topics, expected innovative results)
    - The implementation of the project and the foreseen activities
    - The project partnership (profile and type of the participating partners, EU and non-EU countries)
    - Impact of the project (the impact of the project and its further exploitation after the end of the implementation)

Data protection needs to be safeguarded after the end of the project

Data protection in project implementation

- What sort of situations might involve data processing aspects (including activities with human involvement)?

  - Access to a database containing personal data; management of the database; publication of a photograph of a person on a website; storage of IP or MAC addresses; creation of a mailing list or a list of subscribers, etc.

  - Work with people during: Studies, interviews, people affected by the project activities, collection of personal data, etc.;

    - special attention to special categories of data and work with children and other vulnerable natural persons

  - Important: all partners should have a clear picture of what is at stake and how they should work with the data

Data protection in project implementation

- Identification of potential data protection issues and risks
  - Checkpoints for a clear understanding of the processes to be applied and assess possible risks for data protection:
    - What type of data will you process and for what purpose?
    - How will you process the data?
    - Will you transfer data and if so, to whom and how?
    - Do you have partners or infrastructures outside the EU? Will you transfer data outside the EU?
    - How will you store data and how will you ensure its security?
    - How will you ensure that the data is updated and accurate?
    - How long will it be stored?

Data protection in project implementation

How should a beneficiary/coordinator/partnership proceed?

► Evaluate the specificities of your project and keep track of your data processing activities within the partnership

► Identify the competent and knowledgeable persons and structures in place at each partner to deal with these issues

► Follow-up on issues identified before or during project implementation and decide on the course of action to be followed in each case

► Ensure that these issues are reviewed and verified before the relevant activities are carried out

THANK YOU!

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