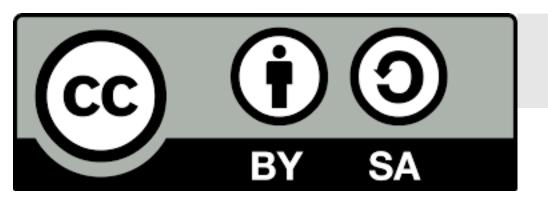
# Ethical Requirements Webminar

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Pilar Orero (UAB) 23 March 2020



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# Why

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#### Charter of Fundamental Rights of the European Union

- This document gathers the fundamental rights to be shared, fostered and protected by every Member State of the European Union. The first draft was created by the European Convention in 2000 and was solemnly proclaimed by the European Parliament, the Council of Ministers and the European Commission during the same year. However, it was not legally binding until the entry into force of the Treaty of Lisbon, on 1st December 2009. The Charter contains 54 articles divided in seven titles: dignity, freedoms, equality, solidarity, citizens' rights, justice and general provisions governing the interpretation and application of the Charter. This Charter must be abode by Member States when applying European Union law.
- The Charter sets the starting point for any research or action conducted within the context of the European Union. Every article needs to be taken into consideration in order to develop a study within an ethical framework, such is the case of any project supported and funded by the European Union. There are certain specific articles that are of high importance when developing the methodology to conduct a research in Social Science. For example, Article 8, Title II (European Parliament, Council and Commission, 2012), on Protection of personal data, which literally states that:
- Everyone has the right to the protection of personal data concerning him or her.
- Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law. Everyone has the right of access to data which has been collected concerning him or her, and the right to have it rectified.
- Compliance with these rules shall be subject to control by an independent authority.





#### Charter of Fundamental Rights of the European Union

Article 26, Title III on integration of persons with disabilities needs to be considered when defining the general vision of the project and its entire development (European Parliament, Council and Commission, 2012): "The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community."



#### European Code of Conduct for Research Integrity

Created by the European Federation of Academies of Sciences and Humanities and has been recently revised and republished in 2017. This document contains a set of rules to self-regulate academic research through European territories and it is designed to be used across all scientific fields, without distinction. It includes the principles to preserve research integrity, a list of good practices and some guidelines about violations of research integrity (the most serious being fabrication, falsification and plagiarism) and procedures to be followed in the event of those violations.

According to this Code of Conduct, the principles to preserve research integrity are (ALLEA, 2017):

- **Reliability** in ensuring the quality of research, reflected in the design, the methodology, the analysis and the use of resources.
- Honesty in developing, undertaking, reviewing, reporting and communicating research in a transparent, fair, full
  and unbiased way.
- **Respect** for colleagues, research participants, society, ecosystems, cultural heritage and the environment.
- **Accountability** for the research from idea to publication, for its management and organisation, for training, supervision and mentoring, and for its wider impacts.

The document describes good research practices in various contexts: research environments; training, supervision and mentoring; research procedures; safeguards; data practices and managements; collaborative working; publication and dissemination, and reviewing, evaluating and editing.

# Horizon 2020 Programme Guidance How to complete your ethics self-assessment

Specific guidance on Social Science and Humanities

The basis to ensure an ethical research is provided by the following tools: informed consent, data protection and privacy, and impact of the research results (European Commission, 2019).

The document acknowledges that "[w]hile in some instances, the research activity itself could produce psychological discomfort or harm, in most cases the biggest risk in SSH research relates to the disclosure of a person's identity and insufficient protection of private information which may then lead to discrimination or stigmatization" (European Commission, 2019: 9).

http://ec.europa.eu/research/participants/data/ref/h2020/grants\_manual/hi/eth\_ics/h2020\_hi\_ethics-self-assess\_en.pdf



#### Vulnerable Groups

European Commission, 2019: 53), vulnerability is a very complex concept and the following indicators could be used to define vulnerable groups:

- 1. Subjects who lack competence will be unable to protect their interests by choosing to give or withhold consent
- 2. If the voluntariness of the subjects' consent is compromised, this may similarly prevent them from choosing to give or withhold consent in a way that would protect their interests.
- 3. The physical (or psychological) condition of some subjects leaves them especially liable to harm, for example as a result of frailty through age, disability, or illness."

Following the Guidance note — Research on refugees, asylum seekers & migrants TRACTION will apply the following principles whenever research involves such participants:

- treat them with care and sensitivity
- be objective and transparent
- avoid ethnocentricity: show respect for their ethnicity, language, religion, gender and sexual orientation
- rigorously safeguard the dignity, wellbeing, autonomy, safety and security of their family & friends
- respect their values and right to make their own decisions





#### TRACTION will include in the ethics self-assessment

- Information on the participants' legal status and any details regarding their specific vulnerability due to their status.
- Confirmation that the research:
- is relevant to the communities involved (both source and host)
- has objectives that are not harmful or prejudicial to participants

A detailed strategy document describing:

- the procedures you will implement to protect participants' best interests and ensure their involvement will not jeopardise safety or increase vulnerability
- how the criterion of relevancy will be satisfied (e.g. by prior consultation with the community itself or a cultural insider)

https://publications.europa.eu/es/publication-detail/-/publication/0f37f142-c333-40a8-90a7-bba25c314720/language-en

http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/guide research-refugees-migrants en.pdf



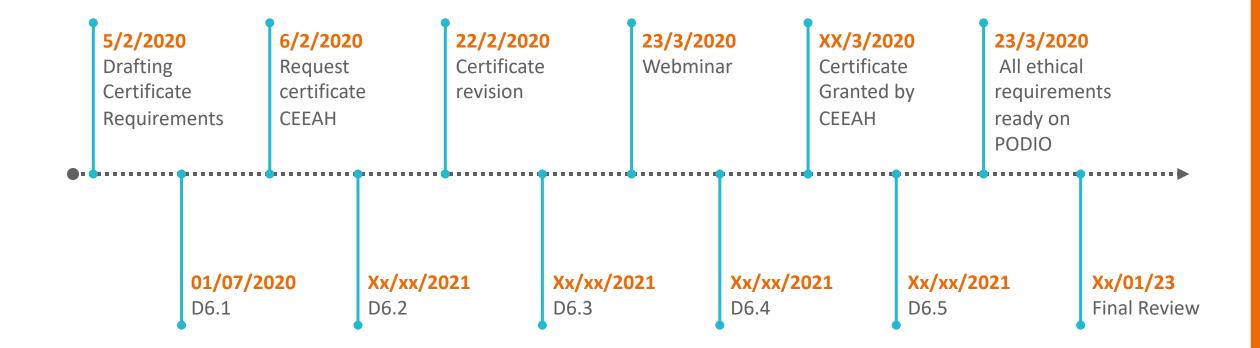


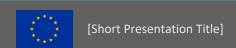
### When

During the project WP6. Ethical Requirements



#### TRACTION Ethic Requirements Timeline WP6







### When

During the project WP2, WP3, WP4, WP5



#### WP3

T3.1 – Liceu – Translate information, consent, and visual right

T3.2 – SAMP – Translate information, consent, and visual right

T3.2 – INO – Translate information, consent and visual into Gaelic

Describe recruitment

Describe interaction with end users

Describe demography, languages



#### WP4

T4.2 CWI - Define UX conditions

T4.3 UAB – Ethical committee certification





#### WP5

Before any video, photograph  $\rightarrow$  Image permission form

#### Example:

All people who attended the KOM 2-4 February 2020 in Vicomtech signed the form.

AP: Check all TRACTION members have signed a form for the duration of the project



### When

Testing/Focus Groups/Interviews/System requirements etc.



#### Before

#### Recruitment

- Consider including researchers with a **refugee or migrant background**, or from the same culture. This may mitigate potential risks of coercion or power differentials between researchers and participants.
- Be aware that such people could also act as gatekeepers or could even amplify power differentials.



#### Before

• Prepare the three forms in the language of participants.

https://drive.google.com/drive/folders/1 JiuC-FZKyWaWFTRvzVH92D8jxGqvUFW

 Make sure people are able to read the document, or prepare alternative communication:

Easy-to-Read

**Translation** 

Read aloud

Interpretation



24/03/2020

#### Data protection

- A detailed strategy to ensure all personal data collected will be kept confidential and anonymous. This will be explained thoroughly to the participants in the Information Sheets or orally.
- TRACTION procedures for data collection, storage, protection, retention, transfer, destruction or re-use (including: collection methodology, digital recording, picture, etc.), exchange (LAN, cloud, etc.), data structure and preservation (encryption, anonymisation, etc.), data merging or exchange plan, commercial exploitation of data sets etc.
- TRACTION data safety procedures (protective measures to avoid unforeseen usage or disclosure, including mosaic effect, i.e. enabling identification by merging multiple sources).
- The specific procedures that TRACTION will implement to ensure the confidentiality and anonymisation/pseudonymisation of personal data about the relocation of participants (especially for participants defecting or leaving their country for political reasons).





#### During

- treat them with care and sensitivity
- be objective and transparent
- avoid ethnocentricity: show respect for their ethnicity, language, religion, gender and sexual orientation
- rigorously safeguard the dignity, wellbeing, autonomy, safety and security of their family & friends
- respect their values and right to make their own decisions



#### During

Each participants needs to sign and understand two/three/four forms:

- 1) Information
- 2) Consent
- 3) Visual Rights
- 4) Property Right





#### After

Will you inform participants of results?

How?

All the signed documents are stored in VICOMTECH 5 years after the end of the project →2027



#### What to include in your report

- Details on recruitment, inclusion and exclusion criteria
- Justify your interactions with vulnerable groups

The reasons may vary but there are common principles: give a rationale for your methodology, including the research subject, choice of research sites, participants and researchers; how you plan to establish a trust relationship with participants; how you will be transparent about future use of findings and their potential harm/benefit for vulnerable groups.

• Do **not create unjustified expectations** in participants about:

future residence in the EU or the determination of their refugee status by any national authorities

how the research will help to improve the situation of their group and how participants will be recognized or rewarded (make sure to avoid undue inducement)

justify why certain volunteers cannot be recruited, to avoid concerns about favouritism and unfair exclusion.

Will you give feedback from the focus group/interview/Project?



## What

**Ethical Requirements Forms** 



#### Information

Storage

https://drive.google.com/drive/folders/16b-69l80Dk8JEBkXpJG56hx3cTX-yDc9

Form in English to be translated/adapted

https://drive.google.com/drive/folders/16b-69l80Dk8JEBkXpJG56hx3cTX-yDc9





#### Consent

Form:

https://drive.google.com/drive/folders/1Y8Zy7CMtdubCMmgVY7lw1Wa9S9IX

**VKre** 

Storage

https://drive.google.com/drive/folders/1 JiuC-

FZKyWaWFTRvzVH92D8jxGqvUFW



#### Visual Rights

Form:

https://drive.google.com/drive/folders/1YirdbjQp5HsInqqiE97Ch292iGAPDlub

To store: each partner has its folder

https://drive.google.com/drive/folders/1YirdbjQp5HsInqqiE97Ch292iGAPDlub



#### Documents for Deliverable 1

- A detailed strategy document describing:
  - the procedures you will implement to protect participants' best interests
     and
- ensure their involvement will not jeopardise safety or increase vulnerability
- how the criterion of relevancy will be satisfied (e.g. by prior consultation with the community itself or a cultural insider)



#### Deliverable: report

- the procedures and criteria that will be used to identify/recruit research participants,
- the informed consent procedures that will be implemented for the participation of humans,
- the templates of the informed consent/assent forms and information sheets in the different languages to be administered,
- terms and procedures and criteria that will be used to identify/recruit research participants,
- the measures to protect vulnerable participants and to minimise the risk of their stigmatization,
- whether invasive physical procedures will be used and what measures
  will be taken to minimise possible pain, though there is no physical procedures. This
  point has been raised here because in some cases Head Mounted Displays to visualize
  360° media content may produce dizziness.

# Thank you for your attention

Pilar Orero, UAB, 23<sup>rd</sup> March 2020







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