

CESSDA ERIC

Consortium of European Social Science Data Archives
European Research Infrastructure Consortium



Ethical considerations in creating shareable data

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Social Science Data Archives

Seminar How to Get the maximum from Research Data , Estonia: Tartu, 29. May 2018



Training team at CESSDA ERIC

- Topic specific webinar / workshop (How to find data in Europe, Ageing, Political Behaviour, Migration, Labour Force Survey)
- RDM workshops / summer schools / guides



Source:
<http://www.statistics.gr>

Research Data
Management

Researcher /
producer

Service
providers

SP staff

Data Discovery

Researcher /
user

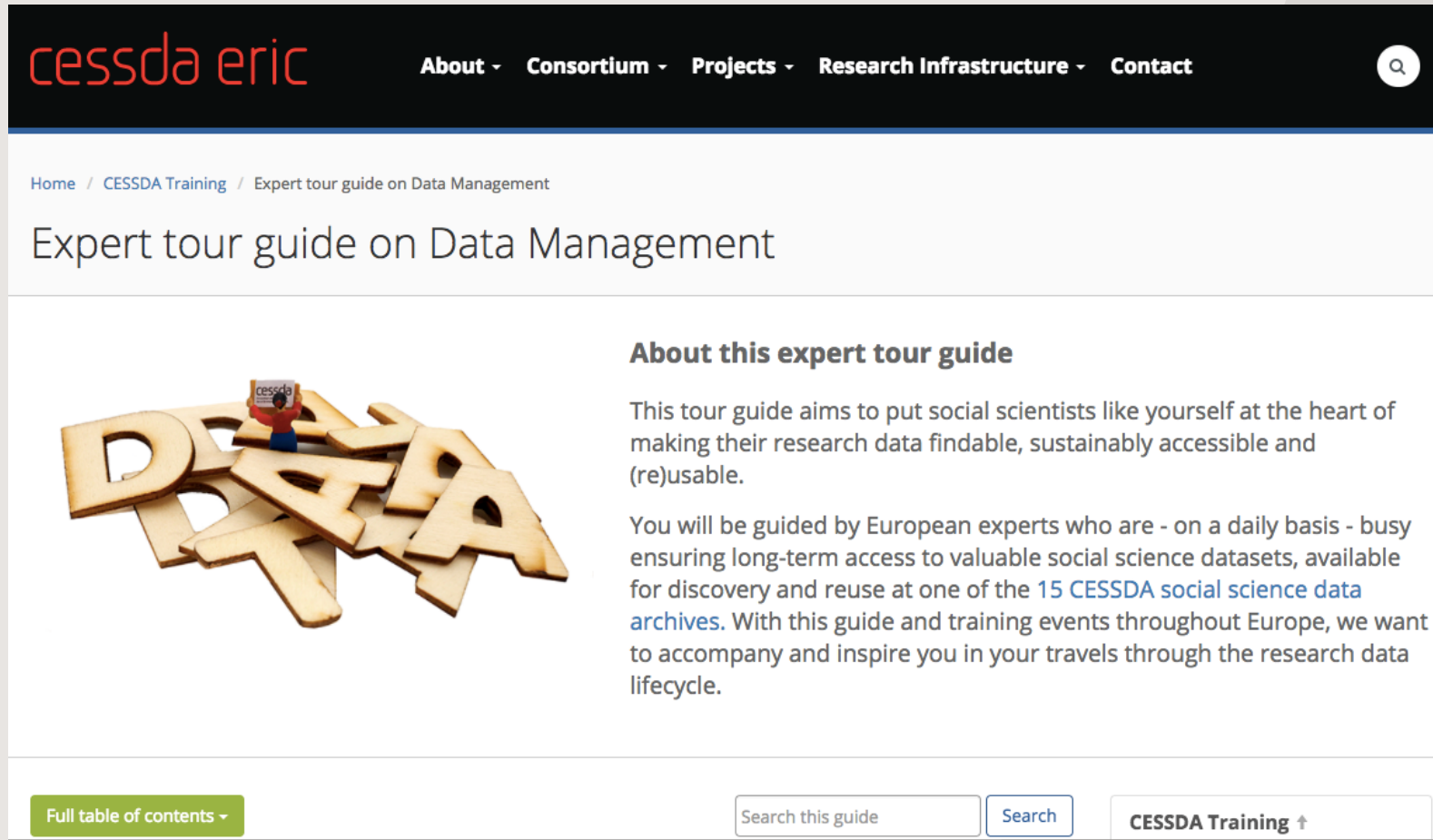
9 Service providers actively involved in 2018 (11 in 2019)

Σ 20 PM / year

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CESSDA Data Management Expert guide


cessda.eu/DMGuide



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Expert tour guide on Data Management



About this expert tour guide

This tour guide aims to put social scientists like yourself at the heart of making their research data findable, sustainably accessible and (re)usable.

You will be guided by European experts who are - on a daily basis - busy ensuring long-term access to valuable social science datasets, available for discovery and reuse at one of the [15 CESSDA social science data archives](#). With this guide and training events throughout Europe, we want to accompany and inspire you in your travels through the research data lifecycle.

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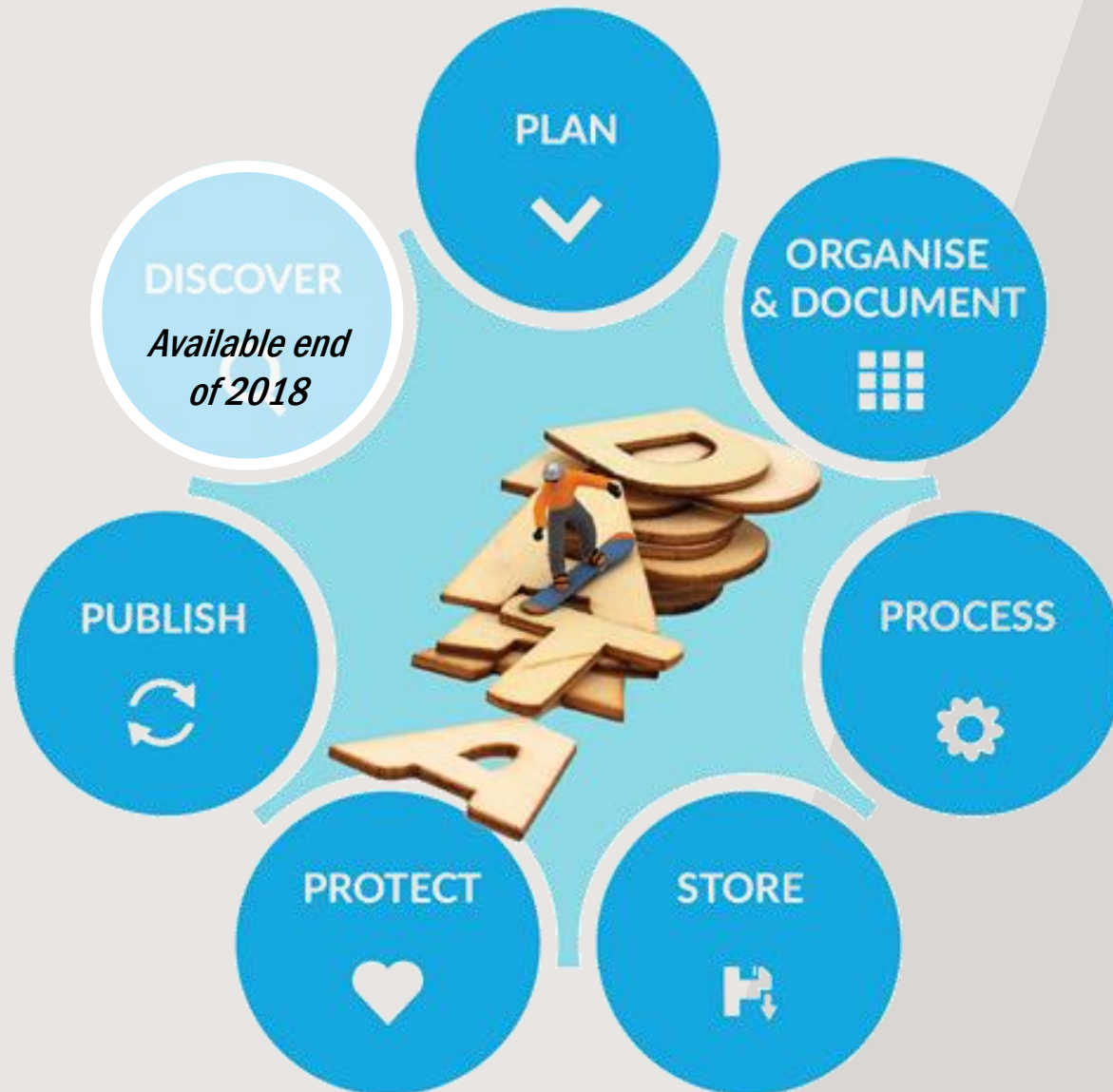
8 content partners

DANS (NL) leading the project

4 testing partners

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Chapters in the expert guide on Data Management



*Presentations
and exercises*

Recurring elements in each chapter

» Expert Tips



» European diversity



Data management requirements in Europe

» Qualitative vs. Quantitative data

» Adapt your DMP



Source: Braukmann, 2018

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Recurring elements

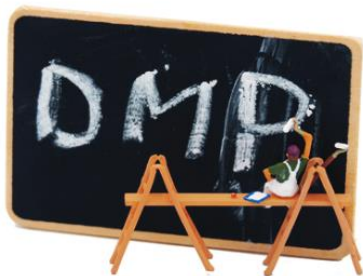
Source: Braukmann, 2018



CESSDA
Consortium of European
Social Sciences Data Archives

Adapt your Data Management Plan

A list of Data Management Questions based on the Expert Tour Guide on Data Management



This CESSDA list of Data Management Questions (2017) is licensed under a Creative Commons Attribution-ShareAlike 4.0 International License.



The CESSDA Expert Tour Guide on Data Management is available at <https://www.cessda.eu/DMGuide>



Overview

Title of the project

Date of this plan

Description of the project

- What is the nature of the project?
- What is the research question?
- What is the project time line?

Origin of Data

- What kind of data will be used during the project?
- If you are reusing existing data: What is the scope, volume and format? How are different data sources integrated?
- If you are collecting new data can you clarify why this is necessary?

Principal researchers

- Who are the main researchers involved?
- What are their contact details?

Collaborating researchers (if applicable)

- What are their contact details and their roles in the project?

Funder (if applicable)

- If funding is granted, what is the reference number of the funding granted?

Data producer

- Which organisation has the administrative responsibility for the data?

Project data contact

- Who can be contacted about the project after it has finished?

Data owner(s)

- Which organisation(s) own(s) the data?
- If several organisations are involved, which organisation owns what data?

Roles

- Who is responsible for updating the DMP and making sure that it's followed?
- Do project participants have any specific roles?
- What is the project time line?

Costs

- Are there costs you need to consider to buy specific software or hardware?
- Are there costs you need to consider for storage and backup?
- Are potential expenses for (preparing the data for) archiving covered?

Adapt your DMP: Part 1

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Search this guide

Search

The Data Management Plan (DMP) is an important tool to structure the research data management of your project. After working on each chapter you should be able to answer part of the questions which make up a DMP.

This is the first of six 'Adapt your DMP' sections in this tour guide.

When you have finished the chapter on data management planning, you can start filling in the 'Overview of your research project' section. Below you can see what elements and corresponding questions are generally included in that section. You can select appropriate questions and answer them to adapt your own DMP.

For easy reference, we have put together a list of DMP-questions for all chapters in this tour guide. You can [view and download it](#) (CESSDA, 2017) and keep it as a reference while you are studying the contents of this guide.

- + Title of the project
- + Date and version of this plan
- + Description of the project
- + Origin of the data
- + Principal and collaborating researchers
- + Funder (if applicable)
- + Data producer
- + Project data contact
- + Data owner(s)
- + Roles
- + Costs

5. Protect

Ethics and data protection

Ethical review process

Processing personal data

Diversity in data protection

Informed consent

Anonymisation

Copyright

Diversity in copyright

Adapt your DMP: part 5

Sources and further reading

This chapter highlights legal and ethical obligations and shows how a combination of gaining consent, anonymising data, gaining clarity over who owns the copyright to your data and controlling access can enable the ethical and legal sharing of data.

Authors

Scott Summers



Libby Bishop

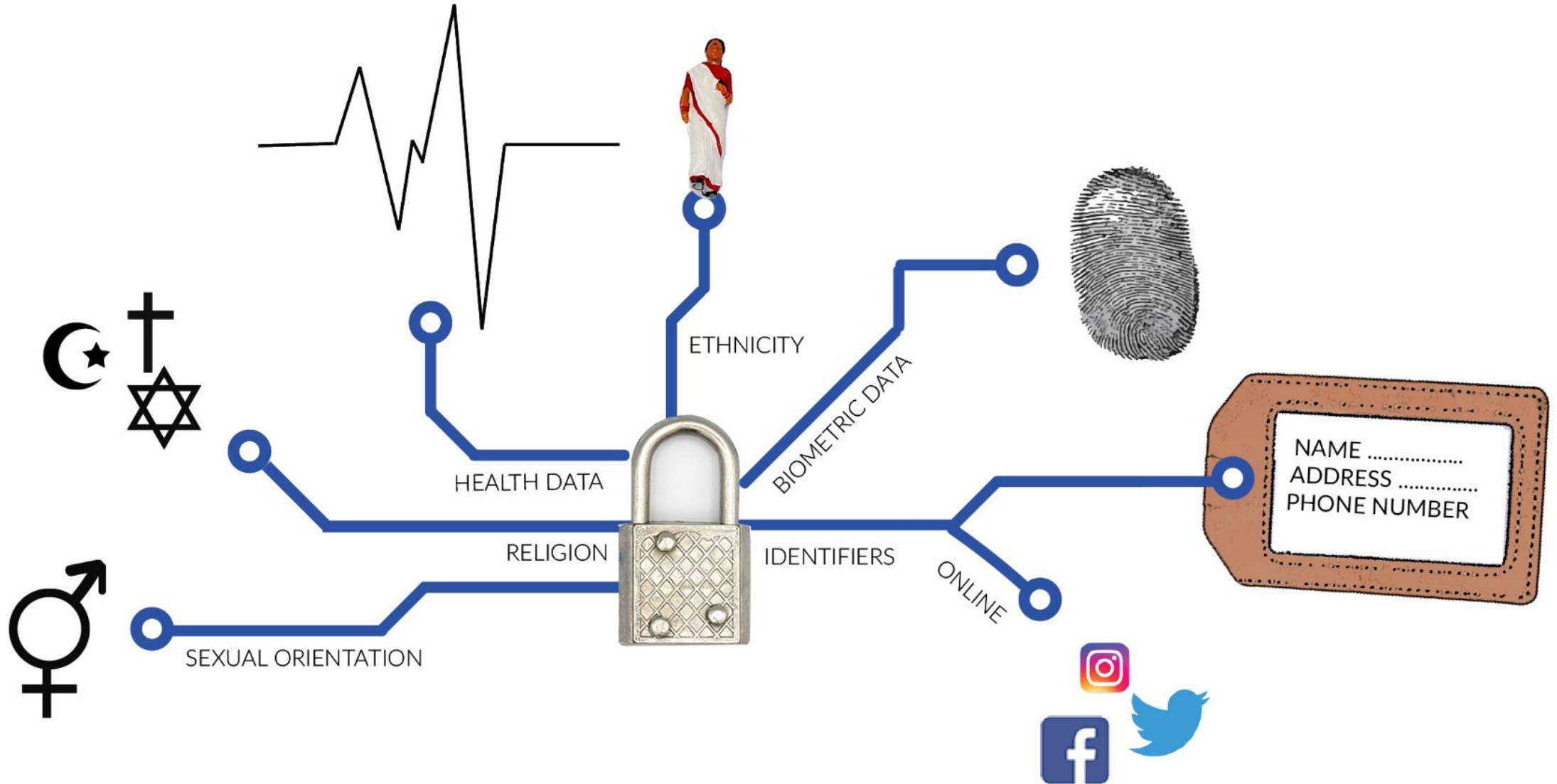


UK Data Service



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Sensitive personal data



Research Ethics

Disciplinary Code of Ethics (ASA)

National Code of Ethics – Soc. Assoc.

[European Code of Research Integrity](#)

University ([UNI-LJ](#))

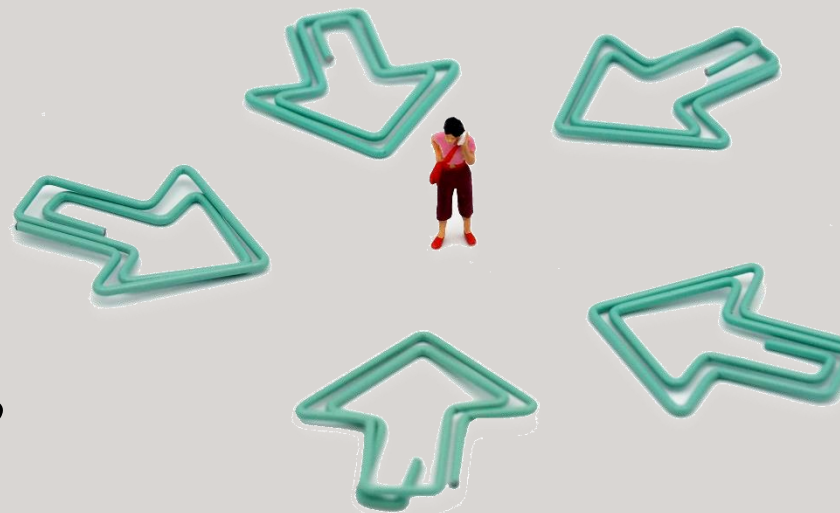
Institute

Funder – H2020 / other EC projects / grants

Scientific Journal <-ethical committee approval before publishing

Ethics are an **integral part of a research project**, from the **conceptual stage** of the research proposal to the **end** of a research project.

Research Ethic
Committee



ASA Code of Ethics

“This Code of Ethics articulates a common set of values upon which sociologists build their professional and scientific work. The Code is intended to provide both the general principles and the rules to cover professional situations encountered by sociologists. It has as its primary goal the welfare and protection of the individuals and groups with whom sociologists work. It is the individual responsibility of each sociologist to aspire to the highest possible standards of conduct in research, teaching, practice, and service.”

[source](#)

-> **Requires a personal commitment to a lifelong effort to act ethically.**

ASA – General principles

A. Professional Competence

only the task for which they are qualified; ongoing education; consult with other

B. Integrity

honest, fair, and respectful of others; inspire trust and confidence

C. Professional and Scientific Responsibility

adhere to the highest sci. and prof. standards and accept responsibility for their work;
don't compromise public trust

D. Respect for People's Right, Dignity and Diversity

They strive to eliminate bias in their prof. activities, and they do not tolerate any forms of discrimination based on age, gender, race, ethnicity ...

E. Social Responsibility

responsibility to the communities and societies; make public their knowledge in order to contribute to the public good

Guidelines for ensuring compliance with ethical principles in Horizon 2020 / **Main ethical principles**

1. Respecting **human dignity and integrity**
2. Ensuring **honesty and transparency** towards research subjects and, notably, getting free and informed consent (as well as assent whenever relevant)
3. Protecting **vulnerable persons**
4. Ensuring **privacy and confidentiality**
5. Promoting **justice and inclusiveness**
6. **Minimising harm and maximising benefit**
7. **Sharing the benefits** with disadvantaged populations, especially if the research is being carried out in developing countries
8. **Maximising animal welfare**, by ensuring replacement, reduction and refinement in animal research
9. Respecting and protecting the **environment and future generations**
10. Following the highest **standards of research integrity** (i.e. avoiding any kind of fabrication, falsification, plagiarism, unjustified double funding or other type of research misconduct)

Ethical Review Process

Is about helping you as a researcher to think through the ethical issues surrounding your research.

The principles of good research practice encourage you to consider the wider consequences of your research and engage with the interest of your participants.

Ethics review by a **Research Ethics Committee (REC)** is typically required when **(sensitive) personal data are being collected or when people are involved.**

The role of a REC is to protect the safety, rights and well-being of research participants and to promote ethically sound research.

Among other duties, this involves ensuring that research complies with national and international data protection laws regarding the use of personal information collected in research.



How to complete your ethics self-assessment (H2020)

“Consider that ethics issues arise in many areas of research. Apart from the obvious example, the medical field, research protocols in social sciences, ethnography, psychology, environmental studies, security research, etc. may involve the voluntary participation of research subjects and the collection of data that might be considered as personal. **You must protect your volunteers, yourself and your researcher colleagues.**

Start thinking about ethics while designing your research protocols. Don't wait until the last minute to seek advice or check requirements under national and EU law.

Your first source should always be at your institution (specialised ethics departments or ethic advisers UNI, hospital research ethics committees, data protection officers). “

Research involve human participants? (H2020)

Are they volunteers for social or human sci. research?	Details of recruitment, inclusion and exclusion criteria and informed consent procedures.
Are they persons unable to give informed consent (including children / minors)?	Details of your procedures for obtaining approval from the guardian / legal representative and the agreement of the children or other minors. What steps will you take to ensure that participants are not subjected to any form of coercion?
Are they vulnerable individuals or groups	Details of the type of vulnerability. Details of recruitment, inclusion and exclusion criteria and informed consent procedures. These must demonstrate appropriate efforts to ensure fully informed understanding of the implication of participants.
Are they children/ minors?	Details of the age range. What are your assent procedures and parental consent for children and other minors? What steps will you take to ensure the welfare of the child or other minor? What justification is there for involving minors?

Research involve human participants?

Are they patients?	What disease /condition/disability do they have? Details of recruitment, inclusion and exclusion criteria and informed consent procedures. What is your policy on incidental findings?
Are they healthy volunteers for medical studies?	/

Physical intervention (human cells, biological samples)... -> Risk assessment

Potential misuse of research results -> Risk assessment

[source](#)

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Personal data (H2020 – Self-Assessment)

Does your research involve **personal data collection and/or processing**?

Does it involve the collection or processing of sensitive personal data (e.g. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction)?

Does it involve processing of genetic information?

Does it involve tracking or observation of participants (e.g. surveillance or localization data, and Wan data, such as IP address, MACs, cookies etc.)?

Does your research involve further processing of **previously collected personal data ('secondary use')** (including use of pre-existing data sets or sources, merging existing data sets, sharing data with non-EU member states)?

[source](#)

Personal data – information to be provided

Details of your procedures for data collection, storage, protection, retention, transfer, destruction or re-use (including, collection methodology (digital recording, picture, etc.), methods of storage and exchange (LAN, cloud, etc.), data structure and preservation (encryption, anonymisation, etc.), data-merging or exchange plan, commercial exploitation of data sets, etc.).

Details of your data safety procedures (protective measures to avoid unforeseen usage or disclosure, including mosaic effect, i.e. obtaining identification by merging multiple sources).

Details of data transfers to non-EU countries (type of data transferred and country to which it is transferred).

- >Copies of notifications/authorisations for collecting and/or processing the personal data (if required).
- >Informed Consent Forms + Information Sheets + Other consent documents (opt-in processes, etc.) (if relevant).
- >Copy of authorisation for data transfer to non-EU country (if required)

The ethical and legal sharing of data

Respect Ethical standards!!!!

Use a combination of consent, information sheet, anonymising data, gaining clarity over who owns the copyright to your data and controlling access.

Informed consent is the process by which a researcher discloses appropriate information about the research so that a participant may make a voluntary, informed choice to accept or refuse to cooperate

Consent is needed across the data lifecycle

Engagement in the research process

What activities are involved in participating in the project?

Dissemination in presentations, publications, the web

Consent for use of quotes for articles and video publicity

Data sharing and archiving

Consider future uses of data

* Consent is always dependent on the research context – special cases of covert research and verbal consent

Source: Summers, 2018

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Informed Consent – Research (1)

To obtain informed consent in practice, researchers should:

- Inform participants about the purpose of the research;
- Discuss what will happen to their contribution (including the future archiving and sharing of their data);
- Indicate the steps that will be taken to safeguard their anonymity and confidentiality;
- Outline their right to withdraw from the research, and how to do this.

Source: Summers, 2018

Informed Consent – Data Sharing (2)

The best way to achieve informed consent for data sharing is to **identify** and explain the possible **future uses** of their data and offer the participant the option to consent on a **granular level**.

For example, in a qualitative study, this may involve allowing the participant to consent to data sharing of the anonymised transcripts, the non-anonymised audio recordings and the photographs.

Source: Summers, 2018

Information Sheet

A/ General information about the research and the collected research data

Purpose of the research

Type of research intervention, e.g. questionnaire, interview, etc.

Voluntary nature of participation

Benefits and risks of participating

Procedures for withdrawal from the study

Usage of the data during research, dissemination and storage, including how the information will be shared with participants and any access and benefits-sharing that may be applicable (e.g. traditional knowledge under the Nagoya protocol)

Future publishing, archiving and reuse of the data, explaining to participants the benefits of data sharing and indicating whether research data will be deposited in a data repository, naming the organisation responsible for the repository (e.g. UK Data Service, your institutional repository)

Contact details of the researcher, with institution, funding source, how to file a complaint

Information Sheet

B/ Additional information if personal information is collected from participants (for example their name, where they live, information that can disclose their identity)

How personal information will be processed and stored, and for how long (e.g. signed consent forms, names or email addresses in online surveys, people's visuals in video recordings)

Procedures for maintaining confidentiality of information about the participant and information that the participant shares

Procedures for ensuring ethical use of the data: procedures for safeguarding personal information, maintaining confidentiality and de-identifying (anonymising) data, especially in relation to data archiving and reuse

Sources

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Questions

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