



# Ethics in Social Science and Humanities

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## Table of Contents

1.	Introduction.....	3
2.	General principles/underlying ethical principles.....	4
3.	Ethical dimensions of research methodology .....	5
3.1	Use of deception .....	6
3.2	Covert research .....	7
3.3	Internet research and social media data in research .....	8
3.4	Research participation .....	11
3.5	Vulnerable participants.....	11
3.6	Children in research .....	12
4	Informed consent .....	13
5	Findings outside the scope of the research: ‘unintended/unexpected/incidental’ findings	14
6	Data protection and privacy .....	15
7	Sites of research .....	16
7.1	Risks, harm and risk assessment.....	18
7.2	Risks and harm in SSH .....	18
7.3	Risk assessment .....	19
7.4	Checklist for higher-risk SSH research .....	20
8	Misuse of research .....	21
9	Ethics approval in SSH research .....	22
10	Management of ethics issues .....	23
11	Other issues.....	23
12	References, links.....	24

## 1. Introduction

This document aims to help researchers in social sciences and humanities (SSH) identify and address ethical dimensions when involved in research and innovation actions financed by the EU Framework Programme. It is also designed to help the wider research community deal with the ethical issues that may arise in interdisciplinary research using SSH methodology. Used together with other guidance documents provided by the European Commission, it should help you integrate research ethics in your proposal and your research.<sup>1</sup>

Rapid technological development and political upheavals in recent years have raised new research ethics concerns, requiring sensitivity to identify ethically problematic areas in SSH research. Increasing use of the internet and social media data in research methodology is a case in point. Crises outside the Europe Union (EU), coupled with migration, have given rise to new, socially important issues, requiring the involvement of new, potentially vulnerable groups of people in research, but also calling for social science research in crisis areas.<sup>2</sup> The many important topics to be addressed by SSH research demand attention to research ethics. It is important to guarantee safe conditions for research participation for people who may benefit from research, but also for researchers themselves.

Much of the advice below is widely available in various literature and guidance documents published by funding bodies, communities of SSH researchers, learned societies and professional organisations. Their role continues to be central for SSH researchers. This document is designed to give practical advice on integrating ethics into the planned research by providing, wherever possible, checklists for points at which a pause is needed to reflect and plan the action to be taken.

While this document focuses on more formal aspects of research ethics compliance associated with SSH research, it also draws attention to ethics in research practice and day-to-day research work, and identifies ways to integrate ethical conduct in your research. Hence, it highlights two ethical dimensions of research: ‘procedural ethics’, pertaining to the aspects of compliance in performing research, and ‘ethics in practice’, the everyday ethical issues that arise while doing research.<sup>3</sup>

According to the European Charter for Researchers, researchers should focus their research for the good of mankind and for expanding the frontiers of scientific knowledge, while enjoying the freedom of thought and expression, and the freedom to identify methods by which problems are solved, according to recognised ethical principles and practices.<sup>4</sup>

Indeed, perhaps more than any other professionals, academic researchers enjoy great freedom to explore their professional interests, investigate a wide range of phenomena and set their own research agenda. In fact, respect for academic freedom is stipulated in Article 13 of the Charter of Fundamental Rights of the European Union<sup>5</sup> (2000), which is legally binding on EU member states.

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<sup>1</sup> This text is a revised version of a Guidance Note written in 2010 to address the needs of applicants and evaluators under the 7th Framework Programme.

<sup>2</sup> For research involving refugees, please refer to the [Guidance Note – Research on refugees, asylum seekers & migrants](#).

<sup>3</sup> Marilyns Guillemin & Lynn Gillam. (2004). ‘Ethics, Reflexivity, and ‘Ethically Important Moments’ in Research. *Qualitative Inquiry* 10, p. 263.

<sup>4</sup> European Charter for Researchers. (2000). Available at: <https://euraxess.ec.europa.eu/jobs/charter/european-charter>

<sup>5</sup> Charter of Fundamental Rights of the European Union (2000). Available at: [http://www.europarl.europa.eu/charter/pdf/text\\_en.pdf](http://www.europarl.europa.eu/charter/pdf/text_en.pdf)

Academic freedom has its limits, however, and a researcher has considerable responsibility to

- the people involved in the research and their rights, safety, well-being and interests (or dignity, integrity, rights, and autonomy)
- communities that are engaged and involved in the research; and
- society at large, in terms of the contributions research can make in effecting socially useful and valued development and change, but also in terms of avoiding potential misuse or unintended consequences of research results.

The European Charter for Researchers, moreover, calls attention to limitations to academic freedom that may arise through particular research circumstances (including supervision, guidance, management) or operational constraints, e.g. for budgetary or infrastructural reasons. The Charter reminds us that '*[s]uch limitations should not, however, contravene recognised ethical principles and practices, to which researchers have to adhere.*'

By acknowledging their responsibilities, social scientists help build and maintain the trust of various social groupings – whether research participants, collaborators, members of the public, or funding bodies – that is necessary to conduct social science research in the first place.

Social scientists commonly face ethical problems, and although ethics can be considered an everyday aspect of research practice, they are becoming more complex.<sup>6</sup> SSH research is dynamic, progressive and developmental, raising new issues and concerns as new foci for research evolve and new ways to collect and analyse data become possible. There is a need for ethically sensitive decisions at all stages of the research process. As a researcher, you are therefore encouraged to engage in continued reflection on any new ethical concerns that emerge while performing your work and on their potential implications for your own work, your research participants, communities and society in general. Moreover, you are encouraged to document and share such concerns within your project and your community of researchers.

Ethics review of all scientific projects start with the question of whether the research objectives raise any ethical questions. From the scientific point of view, every research proposal must address the question of why the planned research needs to be conducted, whether there is any new knowledge to be gained, and whether it is worth spending the time and money to obtain it. Justifying the conduct of any proposed research project means demonstrating that it will offer benefits to scientific understanding, to policy and/or to practice, or to social actors in general, thus making the resources spent on research worthwhile.<sup>7</sup>

## 2. General principles/underlying ethical principles

As a researcher you have an over-riding obligation to protect participants' welfare and safety and to ensure they are treated fairly and with respect.

Research participants' rights are anchored in fundamental human rights and the fundamental ethical principles that govern all scientific research. In the context of research funded by the European Commission, the key sources of EU and international law are the **Charter of Fundamental Rights of the European Union** and the **European Convention on Human Rights (ECHR)** and its Protocols (for other texts). Other important sources are the **UN Declaration of Human Rights** and the **UN Convention on the Rights of Persons with Disabilities (UN CRPD)**. Additional central policies and widely accepted declarations that codify principles of research ethics and ethical treatment of

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<sup>6</sup> Israel, *Ibid.*, p.4.

<sup>7</sup> Ron Iphofen (2009). *Ethical Decision-Making in Social Research. A Practical Guide*, London: Palgrave Macmillan, p. 19. See also, Paul Ransome (2013). *Ethics & Social Values*, Palgrave Macmillan, pp. 30-32.

research participants include the **Nuremberg Code**, the **Helsinki Declaration**, and the **Belmont Report**. Although these codes originate in the biomedical field, they encompass the central principles that apply to all human research. In addition, you are obliged to follow the national legislation of the jurisdiction/country where you plan to conduct your research and the overall principles of EU-funded research.

The basic ethical principles that have evolved to protect human participants from harm, which have their origin in clinical research, apply to all fields of research in which humans participate by contributing time, effort, insights and personal data for researchers' use. These overarching ethical principles in the context of EU-funded research include:

- respecting human dignity and integrity
- ensuring honesty and transparency towards research subjects
- respecting individual autonomy and obtaining free and informed consent (as well as assent whenever relevant)
- protecting vulnerable individuals
- ensuring privacy and confidentiality
- promoting justice and inclusiveness
- minimising harm and maximising benefit
- sharing the benefits with disadvantaged populations, especially if the research is being carried out in developing countries
- respecting and protecting the environment and future generations.<sup>8</sup>

### 3. Ethical dimensions of research methodology

In general, all scientists must consider whether the methodology they have chosen tallies with their objectives and whether the expected benefits outweigh the potential risks. It must be made clear to prospective research participants that they are free to decide whether or not to take part in the research, and whether any data collected from and about them is included in analysis. In most cases, this is secured through obtaining informed consent.

In some rare cases, the anticipated social benefits of the research are so significant that certain individual interests carry less relative weight by comparison. However, these are exceptions in social science research, and strong justification must always be provided.

SSH research is diverse and relies on a multitude of research methods, all of which need specific attention to ethics. The section below briefly introduces methodologies that need particular attention from the perspective of research ethics. The focus is on methods the use (and justification) of which frequently occupy *Ethics Panels* in the screening and review process of proposals. These include:

- use of deception in research
- covert research
- internet research and social media data in research

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<sup>8</sup> For a more detailed account of ethical principles in H2020, please refer to the Annotated Model Grant Agreement, Version 4.1., 26 October 2017, 258


### 3.1 Use of deception

Use of deception in research means that researchers deliberately lie or trick the participants in the research setting so that the true purpose of the study remains unknown to them (until it is revealed in a debriefing once participation is finished). Researchers include deception in the design of the study if disclosing its real purpose would lead participants to modify their behaviour, thereby distorting the research objective.

Use of deception as part of SSH research has been subject to controversy and debate. It violates the principle of informed consent and, it has been argued, can harm participants, researchers, research professions and society overall.<sup>9</sup> Nevertheless, learned societies for social research argue that there are exceptional, justified uses of deception, as in cases where the study addresses important matters and is expected to reveal something of social significance, which cannot be discovered in any other way.

In general, strong justification must always be provided for having recourse to deception, and any study relying on deception must be so designed as to protect participants' dignity and autonomy, despite the method used.

Information for participants may be withheld from them only when the need to preserve the integrity of the research outweighs the participants' interests, or if it is shown to be in the public interest. If information has been withheld from participants, they will be appropriately informed *after* their participation in such a manner and to such an extent that, to their judgment, the informed consent remains intact. Uses of deception are limited and a study must not rely on deception unless the use of such techniques can be justified by the likelihood that the study will have a significant scientific or applied value, and there is no other way to collect the data.

 In the case of procedures that can cause **physical or mental harm**, information must not be withheld, and no deception must be used.<sup>10</sup> Risk management and harm alleviation strategies must be in place.

- *If your research design includes deception,*
- *provide strong justification for the choice of method by showing the importance of the research objective and demonstrating that your research cannot be conducted in any other way*
- *describe how you will debrief your participants and retrospectively obtain their informed consent*
- *show that the use of deception will not harm your participants socially, emotionally or psychologically and that revealing the real nature of the research will not lead to any discomfort, anger or objections on their part, and finally*
- *obtain local ethics committee approval for your study before it gets under way.*

<sup>9</sup> Israel, p. 96, referring to Hegtvædt (2007).

<sup>10</sup> Code of Conduct Code of Ethics for Research in the Social and Behavioural Sciences involving Human Participants. (2018).

### 3.2 Covert research

Another method that goes against the requirements of informed consent and that can invade participants' privacy is *covert research*. This type of secret or disguised research is rare and should be the exception rather than the rule.<sup>11</sup> Like deception, covert research requires strong justification and a demonstration of clear benefits of the chosen method over any other approach. Matters of social significance must be addressed in the research. Covert research should be avoided in principle, unless it is the only method by which information can be gathered, and/or when access to the usual sources of information is obstructed by those in power.<sup>12</sup>

Circumstances that *may* lend support to using covert methods include settings where research participants change their behaviour because they know they are being studied.<sup>13</sup>

Participant or non-participant observation in non-public spaces or experimental manipulation of research participants without their knowledge should be resorted to only where it is impossible to use other methods to obtain essential data.<sup>14</sup> Informed consent should be sought after the event wherever possible. Here the risk researchers face is, of course, that some participants may not give their consent retrospectively, which would mean that some or all of the data collected could not be used.<sup>15</sup>

Covert research may be used in settings that pose no particular risk to participants or researchers if the anonymity of those being observed is safeguarded. Observing fully public settings may therefore not require consent. Such research must be conducted with respect for privacy:

- no personal data are collected (data are fully anonymised at the point and time of collection)
- data are collected unobtrusively and in accordance with local cultural values, and
- data are collected only in situations where people being studied can reasonably expect to be observed by strangers.<sup>16</sup>

Researchers, however, enter risky terrain if they intend to observe illegal activities where covert investigations by appropriate authorities may already be under way (as when drug cartels or human trafficking are under investigation or paramilitary groups, terrorists or organised gangs are under surveillance). By accident, a researcher may become a witness of or even an indirect accomplice to criminal activity and may eventually be involved in obstructing justice if they fail to report illegal activities to authorities.

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<sup>11</sup> Swedish Research Council. (2017). Good Research Practice.

<sup>12</sup> International Sociological Association. (2001). Code of Ethics.

<sup>13</sup> See for example, British Sociological Association. (2017). Statement of Ethical Practice, Item 14, p. 6.

<sup>14</sup> BSA. Ibid., Item 15, p.5

<sup>15</sup> Ransome. Ibid, p. 46.

<sup>16</sup> Code of Ethics for Research in the Social and Behavioural Sciences involving Human Participants. (2018).



*If you plan to engage in covert research*

- *consult the legal department and the data protection officer (DPO) at your host institution to find out about the legal basis of your research and whether your research design poses any risk of breaking the law;*
- *abroad, ensure that you obtain local ethics approval from your host country as well and make sure the methodology you employ is compatible with the local legislation;*
- *remember that if you are working in non-EU countries, the proposed research must be legal at least in one EU member state;*
- *keep in mind that there are positive disclosure obligations in many EU member states that you must be aware of if you intend to conduct research involving terrorism or other criminal activities, for example;*
- *remember that safeguarding the anonymity of research participants is central. Ideally, where informed consent has not been obtained prior to the research, it should be obtained afterwards.<sup>1</sup>*

### **3.3 Internet research and social media data in research**

The internet has been described as a social phenomenon, a tool and also a (field) site for research.<sup>17</sup> *When processing large amounts of data in your research, bear in mind that all big data research on social, medical, psychological, and economic phenomena engages with human subjects; all these data are people. As a researcher you have the ethical responsibility to minimise potential harm to them.*<sup>18</sup>

Social media have been characterised as web-based and mobile-based internet applications that allow the creation, access and exchange of user-generated content that is ubiquitously accessible. Analysing social media data, in particular Twitter feeds for sentiment analysis, has become a major research and business activity, given the easy availability of web-based application programming interfaces (APIs) provided by Twitter, Facebook and News services. There has been explosive growth in data services and software tools for scraping and sentiment analysis and in social media analytics platforms.<sup>19</sup> In turn, the use of such tools in social science research has become increasingly widespread.

A number of issues have been raised in research that is internet-mediated and/or uses social media data. These relate, among others, to:

- whether all data that are available are also public and whether it is fair to use them in research
- meeting conditions of free and voluntary informed consent in the context of social media research
- anonymity

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<sup>17</sup> Annette Markham & Elizabeth Buchanan. Ethical Decision-Making and Internet Research. Recommendations from the AoIR Ethics Working Committee (Version 2), p.3. Available at:

<http://www.aoir.org/reports/ethics2.pdf>

<sup>18</sup> Matthew Zook et al. (2017). Ten simple rules for responsible big data research. Editorial. Plos Computational Biology, March 30, 2017, p.1. Available at:

<http://journals.plos.org/ploscompbiol/article/file?id=10.1371/journal.pcbi.1005399&type=printable>

<sup>19</sup> Bogdan Batrinca & Philip C. Treleaven. Social media analytics: a survey of techniques, tools and platforms. *AI & Soc* (2015) 30:89–116

- risk of harm through tracing or exposing the social media user's identity and profile
- uncertainty about whether some users being studied are children or belong to other vulnerable groups.<sup>20</sup>

In using social media data in your research, bear in mind that even data sets comprising thousands of tweets involve human beings who could be directly or indirectly affected by research. There is considerable evidence that even anonymised data sets may make individuals identifiable if they contain enough personal information.<sup>21</sup> Research with anonymised data sets may cause harm to a group through, for instance, discrimination against or stigmatisation of entire populations. Consider the 'mosaic effect', *if you plan to combine large amounts of data from various sources that appear not to be attributable to particular individuals in isolation. While they may look relatively harmless in their own right, there is a chance that they may cause a breach of privacy when combined.*<sup>22</sup> Through availability of government data sets and their machine readability the effect is also relevant in social research, as there is a risk that disparate threads can be easily combined in a way that yields private information or information that could be harmful to individuals if placed in a new context.<sup>23</sup> *Linking diverse sources of social media data can produce the same effect.*

If, on assessing the risks, you anticipate any risk of harm to individuals whose data you are using, you must:

- paraphrase all data that will be republished (to prevent others being led to the individual's online profile),
- seek informed consent from people whose data you intend to use in its original form in research outputs, or
- consider a more traditional research approach that better ensures consent and confidentiality.<sup>24</sup>

Remember that just because data is publicly accessible, that does not mean that it can be processed by anyone for any purpose. When ascertaining whether data is open for use or is to be considered private, bear in mind the online environment where it is posted and the *reasonable expectations of privacy* which the user may have.<sup>25</sup> Password-protected profiles and closed group discussions are obviously intended by their users to be private.

When processing social media platform data:

- make sure you are sensitive to the issues raised
- comply with the EU General Data Protection Regulation (GDPR)
- consult your host institution's data protection officer and/or ethics advisor, and
- find out if you need to obtain ethical approval for collecting data.

For more information, please refer to the document [Ethics and Data Protection](#) (Section: The use of previously collected data ('secondary use')).

<sup>20</sup> Leanne Townsend & Claire Wallace. Social Media Research: A Guide to Ethics. University of Aberdeen. Available from: [https://www.gla.ac.uk/media/media\\_487729\\_en.pdf](https://www.gla.ac.uk/media/media_487729_en.pdf)

<sup>21</sup> Markham & Buchanan. Ibid., p. 7.

<sup>22</sup> David E. Pozen (2005.) The Mosaic Theory, National Security, and the Freedom of Information Act. The Yale Law Journal 115:3, Dec 2005, pp. 628-679. Available at: <https://www.yalelawjournal.org/note/the-mosaic-theory-national-security-and-the-freedom-of-information-act>

<sup>23</sup> See, for example, Adam Mazmanian (2014). The mosaic effect and big data. The Business of Federal Technology, May 13, 2014. Available at: <https://fcw.com/articles/2014/05/13/fose-mosaic.aspx>

<sup>24</sup> Townsend & Wallace. Ibid., p. 11.

<sup>25</sup> Alben Kuyumdzhieva. (2018). Data Ethics and Ethics Review Process. Ethics compliance under GDPR. Presentation.

Consider the following if you plan to use social media data in your research:

- Remember that the data you process is about real people.
- Consult the relevant terms and conditions of the platforms you will be using to obtain your data.
- Appreciate that open source does not mean that it is open for use.
- Ascertain whether the data you intend to access is really public (open platforms vs password-protected fora); if the forum is closed, contact the site or group administrator). Seemingly public data may not be available for research.
- Take all relevant precautions to avoid collecting data from children or vulnerable adults through social media and online questionnaires without appropriate authorisations.
- Consider the potential sensitivity of the data and whether users could be harmed if their data are exposed to new audiences. Sensitive data postings relate to criminal offences, use of illegal drugs, financial problems, mental issues and suicidal feelings, extramarital sexual activity, controversial political opinions and activism.
- Closed groups and fora: if there is an expectation of privacy, seek permission from users to use the data and obtain their informed consent.
- Consider the user's reasonable expectation of privacy.
- For all details, consult the document [Ethics and Data Protection](#).

The GDPR includes specific safeguards related to automated processing or profiling of personal data. Please refer to the document [Ethics and Data Protection](#) for more information.

### 3.4 Research participation

No-one is obliged to participate in research. You need to justify why human participation in your planned work is necessary in the first place.

Anyone who considers participating in your research must have a fair chance to judge whether it is worthwhile taking the time and making the effort to share information with you. Usually this is safeguarded through participants giving their informed consent to participation as part of negotiating the terms of the relationship with the research team.

Your research involves human participants if you are recruiting them or actively involving or influencing, manipulating or directing them in any way in your research activities. This means you must seek informed consent and/or implement appropriate safeguards.

- In your self-assessment, provide clear descriptions of your recruitment policy: who you intend to recruit; where and how you will reach your target group; your criteria for inclusion/exclusion.
- Enter 'human participation' in your ethics form if you collect data through online questionnaires, paper questionnaires, interviews, focus groups, observations or workshops – in other words, through any activity in which you interact with research participants and collect their data for your analysis.

### 3.5 Vulnerable participants

If you involve vulnerable participants, you must provide justification for doing so. The obvious question to address is: can the research results be obtained by involving another, less vulnerable, group? Explain how you ensure that the individuals you involve will not be stigmatised, re-traumatised or otherwise harmed through their participation in your research.

Note that some groups are always vulnerable. These include children, people with cognitive impairments, and those who are unable to give informed consent. Other vulnerability is likely to be context-dependent. This means you and your fellow-researchers need to give some thought to whether a particular group is vulnerable, and for what reason.

In general, groups considered vulnerable because of their circumstances may include:

- children
- refugees
- irregular migrants
- sex workers
- people with cognitive impairments
- dissidents
- traumatised people at risk of re-traumatisation (e.g. people from conflict areas, victims of crime and/or violence); and
- people in dependent relationships with the researcher or the research team (e.g. students doing course work with researchers).

Make sure you do not exacerbate people's vulnerability through your research or research participation. In some countries you may need to show evidence of competence and certification in order to work with children and vulnerable adults.

If you plan to involve refugees in your research, please refer to the [Guidance note — Research on refugees, asylum seekers & migrants](#).

Individuals who cannot consent to research participation are sometimes needed as research participants. Check national laws on research involvement of people who cannot consent, as they are likely to differ from country to country.

*If you plan to involve vulnerable individuals in research, describe the risk of exposure to harm to participants (e.g. social, psychological, physical, reputational, economic or emotional).*

- *Be clear about the possible benefits and/or the lack of benefits of research participation: avoid raising unfounded expectations.*
- *Make sure people can opt out of research, e.g. when involving students. If participation is seen as part of course work, meaningful alternatives must be offered. Do not involve participants who are in any way dependent on you or your staff.*
- *If participation in research has the potential to re-traumatise people, take steps to minimise the risk and ensure that your team includes people with the appropriate expertise and skills.*
- *If there is a risk of stigmatisation, take active steps to minimise this risk.*
- *If there is a risk that the research may make participants vulnerable to physical or psychological abuse, take active steps to minimise such risks.*

### 3.6 Children in research

Due justification must be provided for involving children's in research. In addition, you must obtain their assent and the informed consent of their parents or guardians. When involving young children in research, you must monitor their assent for any verbal or non-verbal clues that they may actually disagree or wish to stop participating.

The age at which children can give their informed consent to research participation varies from country to country. You must abide by the relevant laws of the country where you collect the data. See the *documents* [Ethics and Data Protection](#) for additional information.

Depending on national laws, you may require official vetting and authorisation to work with children.

Depending on national/regional/local laws, conducting research in kindergartens and schools may require special authorisation from municipal social services, boards of education, or similar.

## 4 Informed consent

Most social science research endeavours are such that human participation requires evidence of the voluntary, free, and informed consent of those who contribute their time, insights, effort and data for the use of researchers. Informed consent, whether in writing (as is most usual) or given orally, is thus the default option. Obtaining informed consent, however, does not in itself guarantee ethical research. In some research settings, this very act and the aim of safeguarding participants' rights and well-being in the research setting may place them at risk of harm in their social context (rather than affording them protection).

There may also be situations in which standard procedures for obtaining written informed consent are culturally or contextually inappropriate to the participants. In such cases, explain how you plan to obtain and document consent by other means (e.g. orally).

*If you have concerns that obtaining written informed consent from participants could expose them to harm, consider other ways for them to document their agreement to participate. These options can be explored together with the prospective participants. In such cases, you must justify your decision and your alternative procedure for obtaining consent in:*

- *your ethics self-assessment*
- *your application for ethics approval.*

When preparing information sheets and consent forms, the following checklist may be helpful:

- Give participants a clear explanation of the aims, overall purpose, methods and implications of the research.
- Explain that participation is voluntary.
- Remind participants that they have a right to withdraw their consent at any time without any consequences.
- Explain the degree of benefit, risks, burden or discomfort involved in participation. Give an estimate of the time and effort expected of participants.

- Explain precautions to ensure participants' safety and provide information on insurance, if there is any.<sup>26</sup>
- Explain who is funding the research and for what purpose.
- Disclose who will benefit from the research.
- Give a firm commitment to protecting respondents' anonymity and privacy (provided that this can genuinely be guaranteed).
- Make a clear commitment to treating personal and sensitive information confidentially.
- Reassure participants that there are secure procedures for analysing any data gathered.
- Explain clearly who will have access to any data that participants provide.
- Consider any unintended/unexpected/incidental findings and explain how you intend to deal with such findings.
- Explain briefly where research findings will be published.
- Offer to provide respondents with further information about research if they ask for it.
- Give the name and contact details of the contact person who can answer any queries participants may have.
- Clarify possible uses to which data may be put in future (if this is envisaged) and clarify whether participants will be asked for consent again if this is the case. Cover any issues relating to copyright of data and other materials used in the research.

Whenever you are collecting personal data directly from research participants, you must seek their informed consent using a procedure that meets the minimum standards of the GDPR<sup>27</sup>. This requires consent to be given by a clear affirmative act establishing a freely given, specific, informed and unambiguous indication of the data subject's agreement to the processing of personal data relating to them.<sup>28</sup> This may take the form of a written statement, which may be collected by electronic means, or of an oral statement. For additional details, see the documents [Ethics and Data Protection](#).

## 5 Findings outside the scope of the research: 'unintended/unexpected/incidental' findings

Social science and humanities research relies on methods that may unintentionally produce findings outside the scope of the original research questions. Fieldwork, observations and interviews can yield information that goes beyond the scope of the research design, thus presenting the researcher with a dilemma: whether to preserve confidentiality or to disclose the information to relevant authorities or services.

Unintended/unexpected/incidental findings may include indications of criminal activity, human trafficking, abuse, domestic violence or bullying. Researchers must inform the participants, or their guardians or other responsible people, of their intentions and reasons for disclosure, provided that doing so does not undermine the act of disclosure. A characteristic of incidental/unexpected findings is that they require the researcher to take some form of action.

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<sup>26</sup> Modified list based on a checklist in Paul Ransome's *Ethics & Values in Social Research* (2013, Palgrave Macmillan, p. 43).

<sup>27</sup> For research involving clinical trials, the processing of data should also comply with the requirements established in the Regulation (EU) No 536/2014 of the European Parliament and of the Council of 16 April 2014 on clinical trials on medicinal products for human use, and repealing Directive 2001/20/EC.

<sup>28</sup> See further Article 7, GDPR and 'Guidelines on Consent under Regulation 2016/679', European Commission Article 29 Working Party, adopted on 28 November 2017.

As a rule, criminal activity witnessed or uncovered in the course of research must be reported to the responsible and appropriate authorities, even if this means overriding commitments to participants to maintain confidentiality and anonymity. There may be a legal obligation to report criminal activity. In some research settings (for example when working with refugees), it may be more appropriate to contact relevant NGOs or agencies with appropriate expertise rather than the authorities.

For guidance on research involving refugees, see the [Guidance note — Research on refugees, asylum seekers & migrants](#).

#### *Incidental findings*

- *Plan ahead by drafting a policy for dealing with unintended, unexpected, or incidental findings that are not harmless.*
- *Inform participants about the limits of the confidentiality that you can offer (the information sheet should cover incidental findings policy). See the Guidance Note on Informed Consent.*
- *Be aware of the legal context in which you conduct your research and consult your host institution's legal department (see also covert research, above) to ensure that your research design is within legal limits.*
- *Include in your work plan a structure for discussing unexpected or incidental findings within your consortium.*

## 6 Data protection and privacy

The main risk faced by a SSH research participant is disclosure of identity and insufficient protection of their private information, associated with discrimination and stigmatisation. Safeguarding privacy and appropriate measures for processing, handling, and storing data are thus central at all stages of research and beyond.

Data protection is both an integral issue for research ethics in Europe and a fundamental human right. It is closely linked to human dignity and the principle that everyone should be valued and respected. If this principle is to guide the development of today's 'information societies', it must be rigorously applied by the research community.

The right to data protection is guaranteed by the **EU Charter of Fundamental Rights** and the **Treaty on the Functioning of the European Union**. It gives effect to the right to privacy by providing individuals with autonomy and control over the way information about them is collected and used.<sup>29</sup> In research settings, data protection creates obligations on researchers to provide research subjects with detailed information about what will happen to the personal data that they collect from them. It also requires the organisations processing the data to ensure it is properly protected, 'minimised' and destroyed when no longer needed.

All individual EU-funded research projects that process personal data must comply with:

- EU and national data protection laws
- ethical considerations
- the values and principles underpinning the EU.

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<sup>29</sup> Article 8, EU Charter of Fundamental Rights.

Particular attention should be paid to research involving profiling, automated decision-making, data mining, big-data analytics and artificial intelligence, as these may pose higher risks to the rights and freedoms of data subjects. The increasing impact of these and other forms of ICT on social and material life is reflected in the letter and spirit of the EU GDPR.<sup>30</sup>

Now that large-scale data collection enabled by internet-mediated research and mobile devices is a reality, the onus is still on researchers and the research data infrastructure at their host institutes to discharge their ethical responsibilities.

For further details of data protection, see the document [Ethics and Data Protection](#).

## 7 Sites of research

Knowledge and understanding based on social science research has the potential to improve people's lives, both in diverse communities within the EU and in non-EU countries. Research is thus necessary and it is often conducted in contexts and geographical areas where the conditions for research work may be risky as regards the safety of participants and researchers themselves. Examples include:

- non-EU countries or regions within them where economic, political, environmental and health conditions may pose risks to volunteers participating in research and/or research staff
- conflict regions
- regions with non-democratic regimes.

Obviously, milieus that pose risks to social scientists can be found in the EU countries as well. Studying criminal activity in all its facets and research in troubled neighbourhoods are a case in point.

If you plan research in countries considered resource poor, provide details of benefit-sharing measures, such as responsiveness to local research needs and procedures to facilitate effective capacity-building. Please refer to the Global Code of Conduct in Resource Poor Settings for more information.<sup>31</sup>

If your research site is located in an area that poses relatively high risks to you or your potential participants, provide clear strategies for keeping your research participants/informants, your research staff and yourself safe. A risk assessment needs to be made in which you should include details of safety measures you intend to take, including training for staff and insurance cover.

### *When conducting research outside the EU*

- *your research must comply with the rules governing EU-funded research and the host country's laws*
- *consult and notify relevant bodies in the country where you are to conduct your research;*
- *apply for formal ethics approval for your research if this is required by national law. Any research you intend to conduct outside the EU must be permissible and legal in at least one EU country.*

<sup>30</sup> EU Regulation 2016/679.

<sup>31</sup> Global Code of Conduct available at: <http://www.globalcodeofconduct.org/wp-content/uploads/2018/05/Global-Code-of-Conduct-Brochure.pdf>



### *Research in regions of higher risk*

*List of overall considerations to apply to research projects in resource poor countries:*

- *Make sure your research is responsive to the needs of the country where it is carried out (e.g. the study has value for the welfare of the intended participants, their community, and/or their country). This issue is of critical relevance for emerging and developing countries.*
- *Where applicable, apply for local authorisation for conducting your research.*
- *Be sensitive to local conditions. Explain how your research proposal fits into local customs and practices.*
- *Show how the results of your research can be applied in low and/or lower middle-income countries.*
- *Show how you are helping build local capacities by conducting research in resource poor countries and how benefits will be shared.*
- *If appropriate, state that you are planning to discuss in advance the planned research and dissemination of the results with relevant parties in the community.*
- *Make sure that your research complies with the rules for EU-funded research and ethics requirements and that it also abides by relevant local, national, international and EU laws and guidelines.*
- *Confirm that the research you plan to conduct outside the EU is legal in at least one EU country.*
- *Find out how to obtain ethics approval in your host country, so that the ethical acceptability of your research is appropriately assessed against customs and traditions at your study site.*
- *Consider the safety of participants and staff, especially if you plan to address sensitive topics (e.g. political views, sexual orientation, religion, trade union membership) or involve marginalised groups. Provide a risk analysis and mitigation strategy.*
- *Research in conflict areas can be justified. If you intend to collect data in a troubled region, devise a strategy for keeping researchers, informants and their associates safe.*

### **7.1 Risks, harm and risk assessment**

A particular characteristic of SSH research is that the methodologies are dynamic, progressive and developmental. This means that anticipating *all* risks relating to a research endeavour at the proposal stage may be very difficult. Nevertheless, you need to devote time to thinking through your research design and making a risk assessment that considers risks from the perspective of the individual and society. Risk assessment is a continuous activity in a project, and your risk assessment document will respond to changes in methodology and, more generally, in the circumstances of the research setting.

While much social science research can be classed as posing minimal or low risks, some such research has the potential for heightened risk.

## 7.2 Risks and harm in SSH

The likely risks and harms in SSH research may differ from those in clinical research. It is important to understand their nature and likelihood in order to set up appropriate collaboration with participants and measures for their protection. As a rule, the potential harm associated with participation in social science research is multifaceted. Addressing such harm appropriately requires care.

Participants in social science studies are seldom exposed to physical harm, although they may sometimes experience transient psychological discomfort or even harm as a result of the research activity itself.<sup>32</sup> Research may be disruptive and damaging to research participants as individuals or to whole communities or categories of people, such as those with HIV infection. Risks can be non-material, including *'risk to a participant's personal social standing, privacy, personal values and beliefs, their links to family and the wider community, and their position within occupational settings, as well as the adverse effects of revealing information that relates to illegal, sexual or deviant behaviour.'*<sup>33</sup>

One of the main risks faced by a SSH research participant, then, is disclosure of identity and insufficient protection of their private information, leading to discrimination and stigmatisation. Safeguarding privacy and appropriate measures for processing, handling, and storing data are thus central at all stages of research and beyond. When engaging in large-scale data collection enabled by internet-mediated research and mobile devices, the onus is still on researchers and the research data infrastructure at their host institutes to discharge their ethical responsibilities.

Participation in research involving risks that have not been appropriately managed may cause harm of various kinds: emotional, psychological, economic, reputational, and legal.<sup>34</sup> Such damage can, at worst, be longstanding and even irreparable.

*In assessing risks, bear in mind that some groups are more vulnerable if the confidential private information they provide is linked with them or traced back to them.*

*They include: victims and witnesses of violence, in particular domestic violence; sex workers; in some contexts, members of minority groups; irregular migrants; refugees; LGBTI persons; patients; disabled people; HIV-positive people.*

*When planning research in a cultural context different from your own, carefully assess the risks facing a potential research participant (and yourself).*

Research ethics issues in SSH research are diverse and sometimes very complex. The risks are varied and need to be systematically addressed according to the research and ethics issues associated with each project. The responsibilities incumbent on the research teams to identify and prevent potential harm can be significant.

## 7.3 Risk assessment

The notion of minimal risk is used to denote research in which the probability and magnitude of harm or discomfort anticipated are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests. Research ethics committees (RECs) sometimes use the threshold of minimal risk as a criterion for requiring a full ethics review.

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<sup>32</sup> Guidance Note 2010.

<sup>33</sup> ESRC Framework for Research Ethics. Updated January 2015.

<sup>34</sup> See Guidance Note 2010, and Joan E. Sieber. *Risk and Harm*. (2004).

The following list provides examples of research that entail **more than minimal risk** according to the *Economic and Social Research Council (ESRC)*:

- Research involving potentially vulnerable groups and people unable to consent;
- Research involving sensitive topics and those which might cause psychological stress, anxiety or humiliation;
- Research involving potentially sensitive topics, such as participants' sexual behaviour; illegal or political behaviour; experience of violence, abuse or exploitation; mental health; participants' personal or family lives; or their gender or ethnic status. Elite interviews<sup>35</sup> may also fall into this category.
- Individuals or groups in cases where a gatekeeper is normally required to give permission for initial or continued access to participants. This includes research involving gatekeepers such as adult professionals (e.g. those working with children or the elderly), or research in communities (within or outside the EU) where access to research participants is not possible without the permission of another adult, such as another family member (e.g. the parent or husband of the participant) or a community leader, and research where participants are in a dependent relationship with the gatekeeper (e.g. employees recruited through their workplace). Permission for access to other groups, for example participants in a long term cohort study, may also need to be requested from a data producer who controls access to the group.
- Research involving justified deception without participants' valid and informed consent at the time the research is carried out;
- Intrusive interventions or data collection methods, such as the administration of substances; vigorous physical exercise; or techniques where participants are persuaded to reveal information which they would not otherwise disclose in the course of everyday life. Also research which would or might induce psychological stress, anxiety or humiliation, or cause more than minimal distress.
- Research where the safety of the researcher may be in question;
- Research involving respondents through the internet, in particular where visual images are used, and where sensitive issues are discussed or where participants and other individuals may be identifiable in the visual images used or generated.
- Social media and participants recruited or identified through the internet, especially if the understanding of privacy in these settings is contentious when sensitive issues are discussed - for example in 'closed' discussion groups where there is potential for quotes to be identifiable, and including those where visual images are used.
- Any research where biological samples are collected and/or medical imaging technologies are used as part of SSH research.

#### *Risk assessment*

- *Provide a clear and adequate assessment of risks in your ethics self-assessment, stating explicitly what kinds of harm might occur and the likelihood of participants experiencing such harm. Be explicit about how you intend to manage risks and mitigate harm. Provide sufficient detail in your risk assessment and justify the choices made.*
- *Remember that any involvement or intervention may involve a risk to the participant and that the onus is on you to establish that there is no risk, that the risk is minimal and justifiable, and that appropriate risk management structures are in place.*

<sup>35</sup> Interviews where an interview partner is chosen on the basis of their position or status, not randomly.

## 7.4 Checklist for higher-risk SSH research

Use the table below to check whether your planned work could potentially involve a higher than minimal risk/increased sensitivity.

<b>Participants</b>	<i>Children, vulnerable groups (e.g. persons unable to consent, minorities, marginalised people, migrants, refugees, victims of abuse and violence)</i>
<b>Sites of research</b>	<i>Conflict regions, sites of historical value to indigenous people, troubled neighbourhoods, non-EU countries or regions within them where the economic, political, environmental and health conditions may pose risks.</i>
<b>Sensitive areas of research</b>	<i>Risk of exposure to harm to participants, researchers; potentially sensitive topics, such as participants' sexual behaviour; illegal or political activities; experience of violence, abuse or exploitation; mental health; participants' personal or family lives; or their gender or ethnic status. Research into criminal activity.</i>
<b>Methodology</b>	<i>Deception, covert research, invasive methods (fMRI for children) as part of interdisciplinary research, profiling and web-crawling</i>
<b>Data processing, sensitive data</b>	<i>Data collection and processing to be implemented – risk of traceability and re-identification through small groups of participants, linking of large amounts of data from different sources; uncertainty whether children are participating; sensitive data</i>
<b>Consequences of research</b>	<i>Potential for misuse of findings (see section 10)</i>

*If your work involves any of the above, you must:*

- provide a clear justification in your ethics self-assessment for choosing an approach that involves higher risk;*
- explain why alternative approaches are not possible (if they are not);*
- identify the risks, and show how you plan to mitigate and manage the risks (risk mitigation plan).*

## 8 Misuse of research

Some research involves materials, methods or technologies or generates knowledge that could be used for unethical ends. Although such research is usually carried out with benign intentions, it has the potential to harm humans, animals or the environment, or society.

Although the risk of misuse of research can never be eliminated, it can be minimised by identifying risks in good time and taking the right precautions.

Professional codes remind social scientists of their responsibility to protect the interests and welfare of groups and individuals with whom and on whom they work, or who are involved in their research efforts. Social scientists must be accurate and truthful when sharing their analyses and reporting their findings. They also need to consider the effects of their involvements and the consequences of their work or its misuse for those they study and other interested parties.<sup>36</sup>

When designing a proposal, consider not only the immediate aims and intended applications of the activities you plan, but also whether your research could serve unethical purposes. An example of this would be a study involving a minority or vulnerable groups or research which develops social, behavioural or genetic profiling technologies that could be misused to stigmatise, discriminate against, harass or intimidate people.

Questions to identify potential misuse include:

- Could the materials/methods/technologies and knowledge concerned harm people, animals or the environment if modified or enhanced?
- What would happen if they ended up in the wrong hands, e.g. among criminals or terrorists, or were used to curtail human rights or civil liberties?
- Could they serve any purposes other than the intended ones? If so, would that be unethical?

Research which could have an impact on human rights concerns includes research on surveillance technologies, new data gathering and data merging technologies (e.g. in the context of big data). However, social research that could lead to discrimination or stigmatisation is also relevant. Risk mitigation measures may include:

- human rights impact assessment, involving human rights experts in your research
- training personnel and/or technological safeguards
- caution when publishing or otherwise disseminating results (e.g. through privacy by design)
- adapting the research design (e.g. using dummy data)<sup>37</sup>.

*If you are planning research that may give rise to concerns about potential misuse, in preparing your proposal:*

- *provide a risk assessment in part B, detailing the risks and how they will be mitigated in order to prevent misuse*
- *provide a risk mitigation strategy*
- *if required, attach copies of authorisations, security clearances and ethics approval*
- *describe in the risk table in the management section what action you would take if the national authorities did not grant authorisation.*

For full details concerning misuse, see the [Guidance note — Potential misuse of research](#).

<sup>36</sup> See, for example, ISA and BSA. Ibid.

<sup>37</sup> [How to complete your ethics self-assessment](#)

## 9 Ethics approval in SSH research

A number of EU member states, associated countries, and countries where EU-funded research takes place have established structures for research ethics approval for all research involving humans, regardless of discipline. In some countries, however, formal research ethics approval is required and provided only for clinical studies involving humans. Such research ethics committees are often not well-suited to assessing the ethical dimensions of SSH research.


*Before submitting your application, check your institutional, local/regional and national requirements concerning ethics approval and availability of research ethics committees for social science research. Including this information in your ethics self-assessment may save you valuable time and effort when the Grant Agreement is drawn up.*

If your institutional/national framework makes no provision for a research ethics committee which you can approach to obtain authorisation or approval for the SSH research you intend to perform, you can consider the following options.

An **ethics opinion** may be given, for example, by:

- the coordinator's institutional research ethics committee
- the institutional research ethics committee of another research partner, or
- a relevant authority in the country (if applicable), which may give its approval.

*If it is not possible to obtain ethics approval, explain why not (your explanation must be backed up by documentary evidence) and show clearly how you will make sure your research meets all ethical and legal requirements.*

 **As a researcher, you must act ethically, regardless of whether you obtain ethics approval.** You are responsible for ensuring that any research you conduct protects the physical, social and psychological well-being of research participants, regardless of the type of approval procedure your research undergoes.

## 10 Management of ethics issues

If your work raises ethics issues, particularly if more than a minimal risk or increased sensitivity are at stake, make sure you set up adequate ethics monitoring structures. These must be clearly identifiable in your work plan and your ethics self-assessment. Make sure that ethical considerations are integrated into the project from the outset, so that they are part of every relevant interaction and will continue to be addressed even after your research has been completed.

Link your self-assessment to your work plan and demonstrate how you integrate research ethics into your work and how you facilitate the identification and discussion of ethical concerns. For example:

- indicate where ethical issues are addressed in specific tasks in relevant work packages
- include an ethics deliverable, and
- define ethics-related milestones where relevant.

Allocate ethics resources in your description of your work and the budget. Bear in mind that you are the main person responsible for handling ethics issues in your project. You must therefore avoid

handing over the task (and responsibility) of addressing ethics to anyone else, especially anyone outside your consortium.

If you decide to seek further guidance from an independent ethics advisor (or an ethics advisory board) with relevant experience in research ethics in the area of your research, give them meaningful opportunities to interact in your project by providing sufficient resources (including budget and meeting time). Keep the advisor and/or advisory board abreast of your work and your reporting schedule and make sure they are fully integrated into your project, so you can include their reports and advice in your periodic reports.

For additional information on involving and collaborating with ethics advisors and advisory boards, see the guidance in [Roles and Functions of Ethics Advisors/Ethics Advisory Boards in EC-funded Projects](#).

## 11 Other issues

### *SSH research as part of multidisciplinary and interdisciplinary research*

SSH research methods are often used as part of multidisciplinary or interdisciplinary research, for example, in technology innovation, human computer interaction research and robotics. When using SSH methods in such research, SSH studies – like any other SSH research – should be conducted using the best available knowledge in the field. Social researchers and research assistants hired to conduct interviews and perform other tasks bringing them into direct contact with participants are required to be competent to carry out SSH research.<sup>38</sup> Respondents and participants have the right to expect competent SSH researchers as collaboration partners.

If your project's main focus is not on SSH, but you plan to use SSH methods and involve participants, you are encouraged to involve people with sufficient SSH expertise and experience in the relevant work to conduct responsible and competent social science research.

In some study designs, physical interventions in research participants are integrated into interdisciplinary SSH research. If a study affects subjects' physical integrity, this part of the research must also comply with the guidelines governing medical research.

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<sup>38</sup> Ransome, *Ibid.*, p.32-33, 41.

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