**Working Paper**

young adullt

# Work Package 10

# Working Paper on Ethical Issues

## South-West University Blagoevgrad (SWU), University of Münster (WWU) & European Research Services GmbH (ERS)

## 21/06/2016

| | |
|---|---|
| **Project Coordinator:** | Prof. Dr. Marcelo Parreira do Amaral (University of Münster) |
| **Project no.:** | 693167 |
| **Project acronym:** | YOUNG_ADULLLT |
| **Project duration:** | 01/03/2016 to 28/02/2019 (36 months) |
| **Duration of WP:** | Months 1 to 36 |
| **Type of document:** | Working Paper |
| **Delivery date:** | Month 3 |
| **Dissemination level:** | Public |

**Content**

## 1. Aim and Objectives of this Working Paper

A fundamental matter of good research is proper ethical conduct; compliance with moral, ethical, and legal principles are not to be considered an addendum to excellent research but are a critical part of research excellence actually.

The aim of this paper is to ensure that all partners are informed about the fundamentals of research ethics, about "best practice" research standards, and about European and national legal provisions. This is a working document and as such will be recurrently reviewed in step with the research and dissemination activities during the project. This paper should provide concrete orientation:

- a framework of general moral, ethical, and legal principles and provisions which create a common ground of shared values and understandings to support the conduct of research in YOUNG_ADULLLT;
- project-specific ethical issues and requirements which need proper consideration and appropriate measures;
- general and specific guidelines for implementing the project tasks in accordance with the principles of research ethics;
- common ground for elaborating further ethics documents/templates to be used in the course of fieldwork, and
- a timeline for recurrent review of activities and update of this document.

## 2. Moral, Ethical and Legal Fundamentals of Research

This section outlines and reflects upon some of the most important principles, legal acts and frameworks which refer to the ethical aspects of research practice and are applicable to the research activities envisaged in the YOUNG_ADULLLT project. In addition to applicable national provisions and legislation, we draw upon a number of international and European conventions and regulatory frameworks when deliberating on moral, ethical and legal aspects of research practice.

In recognizing the unalienable and universal rights and fundamental freedoms of all humans the YOUNG_ADULLLT Consortium restates the *Universal Declaration of Human Rights* (UN 1948) as the fundamental framework guiding its conduct. Furthermore, the Consortium is committed to observe and protect in all its activities – research and dissemination – the rights and values reaffirmed in the *Charter of Fundamental Rights of the European Union* (European Communities 2000) and the *European Convention on Human Rights* (Council of Europe 2010). It is departing from this rights-based understanding of human affairs that the Consortium sets out to deal with ethical requirements in the course of this research project. Respect for the freedom and dignity of all humans but equally fairness, proportionality, democracy and pluralism represent central concerns guiding all our research and dissemination activities. As both our Consortium and our research fields are diverse and multicultural, it is of foremost importance to attend to different philosophical, moral, and ethical viewpoints and approaches. It is against this background, that we recognise the importance of open dialogue and comprehensive and continuous deliberation of ethical requirements in our research project.[1]

[1] For further reading on philosophical and ethical perspectives informing deliberation on research ethics see: EC 2010; Habermas 1990; Rachels & Rachels 2009.

Research and dissemination activities in YOUNG_ADULLLT are also committed to and guided by legal provisions and obligations.[2] While legislation in all EU member countries is consonant with the above mentioned principles there are also national specificities. For this reason, an overview of National Laws of all partner countries in YOUNG_ADULLLT is also included in this Working Paper (see Annex 1). In particular during the preparation for fieldwork it will be necessary to identify the applicable national and/or local legal requirements. Furthermore, mostly concerning issues of privacy and confidentiality related to data management, security, and protection there are also institutional regulations to be observed.

More closely related to research practice, important ethics principles orienting and supporting the conduct of research draw from the *European Textbook on Ethics in Research* (EC, 2010), from the document *Ethics for Researchers. Facilitating Research Excellence in FP7* (EC, 2013a), and from the *Report Gendered Innovations. How gender analysis contributes to research* (EC 2013b). Central principles and guidelines discussed in this Working Paper refer in particular to:

a) *free and informed consent,* reflecting the respect for the autonomy, dignity and voluntariness of individuals, who need to be adequately informed of all aspects related to the research and of their right to withdraw before they are in the position to accord their permission and consent (section 2.1 below);
b) procedures and safeguards in research involving vulnerable and non-competent subjects, indicating the need to raise awareness and understanding of issues related to 'vulnerability', including issues of language and representation (section 2.2 below);
c) balancing potential harms and benefits arising from research participation (section 2.3 below);
d) the importance of ensuring *privacy and confidentiality* concerning the control and disclosure of personal data and information related to *data management, security and protection* in what concerns keeping the information gathered in a secure and confidential manner (section 2.4 below).

These aspects will be discussed in more detail below and applied to research and dissemination activities in YOUNG_ADULLLT (section 3.).

### *2.1 Free and Informed Consent*

One of the most important procedures central to keeping ethical standards in research is securing free, valid informed consent. The United Nations includes free and full consent in its *International Covenant on Civil and Political Rights* (UN-OHCHR 1996) and European research funding adopted it as "one of the most pivotal principles in research ethics […] meant to guarantee the voluntary participation in research" (EC, 2013a, p. 14).

Free and Informed consent consists of three components: *adequate information*, *voluntariness* and *competence* (EC 2010). These imply that, prior to consenting to participation, participants should be clearly informed of the research goals, possible adverse events, and possibilities to refuse participation or withdraw from the research at any time and without any consequences. Furthermore, in order for it to be valid the research participants must also be competent to understand the information and should be fully aware of the consequences of their consent. These principles are important for all types of research, but they are especially critical when the research involves vulnerable adults. Therefore, they require special consideration.

---

[2] Prominent international ethical codes and guidelines include: The Nuremberg Code (1947); the Declaration of Helsinki (World Medical Association 2008) and the European Convention on Human Rights (Council of Europe 2010).

Since the way in which participants are informed is an essential part of the informed consent process, it is very important to decide on how to organize the consent procedure taking into account the specificities of the context. For example, recruiting participants and requesting consent in some institutional settings (e.g. schools) may be perceived by some participants as an obligation for participating in the research. Procedures for securing free and valid consent must include measures to avoid such undue pressure, so that individuals do not feel an inherent obligation to participate. In short, in order for consent to be voluntary and valid it must not include any type of implicit or explicit coercion, deception or manipulation or inappropriate inducements. Furthermore, it is critical to deliberate on the right amount of information used. Informing participants includes disclosing enough information/material – without overloading them – for them to fully realize the objectives, context (e.g., those carrying it out and those funding the research) as well as the impact of the research for themselves and for society, i.e. potential benefits, risks and harms (see below). Related to this, individuals must be able to fully understand and retain the information, which refers to including measures to verify that participants have sufficient mental capacity and competence for consenting. As concerns the quality of information, it is essential presenting the project in an accessible manner to the particular audience both in terms of language and style. Importantly, researchers have to explain what will happen with the collected data during and after the end of the research. And, if the data are retained for further research this needs to be included in the consent procedure. Finally, potential participants need to have the time and space for taking decision for or against participation, including consulting other sources of information.

### *2.2 Research Involving Individuals in Vulnerable Positions: Inequality, Exclusion, Discrimination*

The concept of vulnerability is used in different contexts to refer to a higher propensity of particular individuals or groups for risk, danger of deterioration in conditions or poor outcomes or achievements. Several factors may be seen as causing or influencing vulnerability, for instance: physical (e.g. sickness, disability), emotional/psychological (e.g. mental illness, immaturity, dependence), material (e.g. poverty, homelessness, health care, education), and social (lack of support by family or peer group, absence of guidance in difficult situations, and immediate risks from the environment).[3] As such, vulnerability may be approached from different viewpoints, for instance individual conditions and behaviours, structural and systemic material conditions or also social relations and insecurity, and thus needs to be seen as a multidimensional concept and in relational terms. If participants belong to such kinds of vulnerable groups, this may require special considerations because a number of ethical issues arise (EC 2010, p. 51ff.). Thus, there is need to raise awareness and understanding of issues related to ‘vulnerability’, including issues of language and representation of participants as individuals and groups.

Additional procedures and safeguards need to be designed in order to protect the rights, interests and welfare of vulnerable research participants. This is necessary because a vulnerable person is at higher risk of harm than others in a similar situation or is less able than others to protect themselves from harm. Therefore, researchers need to elaborate a working definition of “vulnerability” and further on clarify it. They should also consider which groups of individuals might be considered vulnerable and why. In any case, an appropriate assessment of the vulnerability of the potential research participants should be completed.

---

[3] The Human Development Report 2014 has dealt with the theme of vulnerability in the context of sustainable human progress (UNDP 2014). See in particular chapters 1 and 3.

In some cases, research may touch on sensitive topics (for instance, perceived failure to start a professional career, problems in school or in the family), which might induce stress, anxiety or even a feeling of humiliation. This requires measures to be taken to prevent the risk of enhancing vulnerability of individuals/groups (see also section 2.3 below). Additionally, it is necessary to find out how issues concerning vulnerable participants relate to other concepts and issues in research ethics, particularly consent. Disregarding this may compromise the consent process.

Assessing vulnerability may lead to excluding groups of people from participation in research, which may reduce the evidence base or result in a lack of data about important aspects. Therefore, a proper evaluation of the inclusion and exclusion criteria should be envisaged prior to the study as they might affect the research outcomes (e.g., the results could be generalizable only to a certain section of the social group). Although there might be good research-based reasons for the exclusion, some exclusion criteria could be considered discriminatory. In a moral sense, it refers to treating some people less favourably than others. Therefore, methodological rationale for excluding any particular group or subgroup of the studied cohort is necessary. Discrimination could be direct or indirect. A group is directly discriminated when its members are treated less favourably than others because of membership of the group itself (e.g. women). A group is indirectly discriminated when it is treated less favourable on the basis of some criterion which is not necessarily associated with membership of the group (e.g. language). Other possible types of discrimination are – active and passive. While active discrimination is easy to perceive, passive is usually not so obvious. It happens when some people are disadvantaged by not treating them differently when some special treatment is required (i.e. treating people the same when there is a reason to treat them differently).

Related to the issues above, there are also questions related to language use and representation of participants (EC 2013b, p. 128ff.). Social phenomena are influenced by language use, for instance practices of naming and representing, which in turn are influenced by dynamic power relations (cf. Stauber et al. 2015). From this viewpoint, it is an ethical concern for researchers to be aware of their own contribution to processes of social reproduction and differentiation and to avoid exacerbating inequalities. In communicating with participants and especially in disseminating results of the research, it is important to avoid stereotypization, pathologization or reduction of individuals or groups to one or more attribute (e.g. gender, ethnic origin, social class, etc.). Spivak (1985) coined the term *othering* to refer to these hierarchical and generalizing ways of speaking about others, which in turn may be reproduced in the ways people act and as such may be viewed as a way of “doing difference” in society (Fenstermaker & West, 1995).

### *2.3 Benefits, Harms and Risks*

Working with vulnerable groups requires researchers to consider some general ethical issues about the main kinds of benefits and harms or risks produced by their research, for example in relation to burden or cost to the participants, potential breaches of privacy and confidentiality or incidental findings. Whereas the principles of consent and respect for privacy were central in previous sections, here the focus is on the kinds of harm that a research might cause (e.g. psychological, emotional, social, etc.), and how these should be minimised. Furthermore, as almost any research involving human subjects involves also some burden or cost to the participants (e.g. inconvenience, expenses of time, energy and/or even money, etc.) researchers should seek to balance such costs with some corresponding benefits (EC 2010, p. 99f.). Incentives to participate in a research project must be fair and must not unduly exceed the range of incentives that the participant normally experiences. Also, there might be different

benefits for participants, researchers, institutions and society at large which should be carefully considered.

Most of our decisions about how to act are based on predicted consequences. However, harms are often difficult to predict with certainty, so negative consequences might also occur. Therefore, in such cases we are dealing with a risk of harm. When assessing risks, we usually take into account their likelihood and the probable amount of the potential harm. And in order to avoid negative consequences we need to know what the acceptable level of risk is. It might be considered that a risk can be acceptable if it falls below a certain threshold level, usually labelled as 'minimal risk'. A risk is deemed minimal if "'having regard to the nature and scale of the intervention, it is to be expected that it will result, at the most, in a very slight and temporary negative impact on the health of the person concerned'", and correspondingly a burden is deemed minimal "'if it is to be expected that the discomfort will be, at the most, temporary and very slight for the person concerned'" (EC 2010, p. 108).

Whenever withholding information from participants is essential if otherwise the research participants would be negatively affected by it, adequate measures should be taken after the study to ensure the participant's understanding of the reasons.

In Social Science research, such as that conducted in YOUNG_ADULLLT, potential negative consequences refer primarily to issues of privacy and confidentiality and concern the harms that can result from (undue) disclosure of personal information (see section 2.4 below). As mentioned above, research may touch on sensitive topics and might induce stress, anxiety or even a feeling of humiliation and this requires measures to be taken to prevent the risk of harm, such as psychological/emotional stress and discomfort. Furthermore, participants must be made aware of potential social harms, such as stigmatization in the peer group or work environment. Finally, explicit information on procedures on incidental findings needs to be disclosed prior to seeking consent, so that participants are aware of potential implications. Researchers must communicate clearly prior to starting research that information pertaining serious illegal behaviour (dealing with drugs, sexual abuse, violence against other persons, terrorism, etc.) may be disclosed to the relevant authorities.

In short, important ethical aspects are related to balancing benefits, risks or harms for participants. For instance, while it is crucial to preserve privacy and confidentiality, there might be certain cases when it is better to make confidential information available to other people or institutions, for example, when information provided confidentially to researchers may be used to benefit the subject or to prevent harm. Careful and case-immanent consideration is key to assessing benefits and potential risks.

### *2.4 Privacy and Confidentiality: Requirements for Data Management, Security and Protection*

Privacy, as a fundamental human right, is interconnected with confidentiality and at the same time linked to data management, security and protection as these are meant to guarantee the former. Here we see a strong connection between research ethics and human rights, pointing to the moral, ethical and legal dimensions of the issue. Privacy and confidentiality are closely related terms.

While privacy refers to "actions where one is accountable only to oneself" (EC 2010, p. 77), confidentiality may be seen as "concerning the protection of personal information" (ibid., p. 79). Privacy includes "control over information about oneself; control over access to oneself, both physical and mental; and control over one's ability to make important decisions about family and lifestyle in order to be self expressive and to develop varied relationships." (ibid., p. 78f.)

Confidentiality concerns the duty of researchers to protect personal information that has been granted access for specific purposes and within the context of specific relationships and agreements. It relates to the informational aspect of privacy and to the duty of not disclosing it without permission. Moreover, confidentiality concerns the ways in which information is communicated (ibid., p. 80).

Against this background, a number of measures have to be taken in order for research to be ethically acceptable: Seeking permission from those concerned to collect, process, and store information (cf. section 2.1 above), thus respecting the right to privacy. 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. For instance, the protection of privacy and identity makes necessary to take measures for anonymization and codification of all identifiable information and for obtaining consent to disclose information collected (for instance in publications and reports). These measures should include steps for participants to access data collected concerning him or her, to have it rectified, released, objected and deleted.

Related to privacy and confidentiality are requirements for data management, security and protection. These aspects are related to a technical framework and security measures designed to guarantee that all personal data are safe from unforeseen, unintended or malevolent use. It requires a set of specific measures with regard to data collection, storage and protection as well as conservation and destruction. In particular, it is required that personal data is

> "a obtained and processed fairly and lawfully;
>
> b stored for specified and legitimate purposes and not used in a way incompatible with those purposes;
>
> c adequate, relevant and not excessive in relation to the purposes for which they are stored;
>
> d accurate and, where necessary, kept up to date;
>
> e preserved in a form which permits identification of the data subjects for no longer than is required for the purpose for which those data are stored." (Council of Europe 1981)[4]

Besides national and institutional provisions, there are a number of national and international regulations to be drawn upon when devising a data management, security and protection framework for the research:

- The *Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data* (Data Protection Directive and Convention 108, Council of Europe 1981) contains key principles for the handling of personal data. The directive provides the framework for the regulation of data protection and privacy issues in the European Member States;
- The *Handbook on European Data Protection Law* (European Union Agency for Fundamental Rights 2014) provides an overview of the law applicable to data protection in relation to the European Union (EU) and the Council of Europe (CoE);

[4] for a detailed discussion of the single aspects, see European Union Agency for Fundamental Rights (2014).

- The ISO/IEC norm 27001:2013 (ISO 2013) specifies the requirements for establishing, implementing, maintaining and continually improving information security management systems.

## 3. Research Ethics Requirements and Measures in the YOUNG_ADULLLT Project

The previous sections have dealt with various aspects related to ethical questions in research activities more generally. This section focuses on research ethics requirements and measures adopted in the specific context of the project YOUNG_ADULLLT. As the consortium of the YOUNG_ADULLLT project comprises 15 partners from nine European countries operating in quite different contexts, it is of utmost importance to be aware and comply with the various international, European, national and/or regional/local as well as institutional requirements and legislation. In order to have a clear structure and idea about the regulations that need to be adhered to, the consortium has compiled all requirements on National Data Requirements and Institutional Data Security Protocols. Adherence to these laws and regulations will be observed throughout the entire research process.

In the course of the research process of YOUNG_ADULLLT, several of the aforementioned ethical issues will become relevant within the single Work Packages. Some of these issues will become apparent and relevant only in the course of the preparations and implementation of research activities. This make it necessary for the continuous deliberation and review/update of the considerations and measures detailed in this Working Paper. In the following, requirements and measures envisaged will be detailed along the different Work Packages.

### *Work Packages 2 & 3*

WP2 (*Launching and Research Design*) and WP3 (*Policy Mapping, Review and Analysis*) involve primarily analytical desk research. In particular, attending to issues related to language use and representation of participants will become significant. Especially, research – and later dissemination – activities require careful consideration of the ways in which the target groups of Lifelong Learning Policies, in large part young adults in vulnerable positions, are defined and depicted. An important ethical concern is to avoid practices of othering, stereotypization, stigmatization and the like, thus preventing the reproduction or exacerbation of inequalities and discrimination.

Measures to be taken include careful conceptual consideration of the topic during the preparation and implementation of analyses, for instance making researchers aware of these processes and providing knowledge of alternative communicative practices that avoid or minimise them. The Consortium is producing a glossary of terms central to the project with the aim of ensuring a common conceptual understanding of the key elements of the project. Specifically, of key importance to avoiding enhancing vulnerability of participants is devising adequate working definitions, e.g., of ‘young adult’ or ‘vulnerability’, that are not value-laden or stigmatizing, for instance based on deficitary or normalizing assumptions.

### *Work Packages 4, 5 and 6*

Work Package 4, 5 and Work Package 6 (*Comparative Analysis Skills and Demand and Supply*) include quantitative and fieldwork research involving human participants, requiring consideration of a number of ethical issues.

WP4 (*Quantitative Analysis of Young Adults’ Social and Living Conditions*) is concerned with assessing – by means of secondary analyses – to what extent and how living conditions of young adults mediate and influence LLL policies. Data collected and analysed are (a) quantitative socio-economic (macro-level) data on different dimensions of labour market and education/training in participating countries and (b) quantitative data on the specific living

conditions of young adults in regional contexts. A concern at this point refers to the risk of creating a mosaic effect, meaning that by merging large data sets from different sources may endanger data security. After careful consideration, we confirm that there is no risk of a mosaic effect since no datasets will be brought together. In the YOUNG_ADULLLLT research, datasets used contain no personal information and will be analysed separately. Moreover, the data analysed is publicly available from the Internet portals of international organisations and of national official agencies, without any previous requesting of permissions.

Both WP5 (*Qualitative Research with Young Adults*) and WP6 (*Comparative Analysis Skills Supply and Demand)* aim at obtaining and analysing data through qualitative methodologies, mainly via individual and focus group interviews with individuals of an indicative age of 18-29 (N=150) and with experts from policy, employment and training/providers (N=100). Requirements and measures adopted include:

- Identification and recruitment of participants

Research participants will be identified and recruited for interviews according to the specific procedures and criteria for selection developed for national/regional data collection. Results from Policy Mapping, Review and Analysis (WP3) will provide the necessary contextual information to define the context-specific recruitment strategies and criteria to include and exclude different types of research participants by taking into account the policies adopted by the member states. In general, research participants will be identified and recruited via written invitation in their educational and professional/training setting – e.g., upper secondary schools, tertiary education colleges/universities, adult education schools, higher education institutions, vocational training centres, schools and firms (in dual systems), job centres, social service departments and civil society organizations. These institutions will serve only as sites where for instance posters, flyers, etc. inviting for participation may be placed, but they are otherwise not active in order to preclude undue pressure, for instance that young people feel an inherent obligation to participate. *First*, researchers will contact schools/training facilities and request initial consent from institutional representatives (e.g., principals and rectors, responsible trainers, etc.) to place informational material for young adults in these educational/professional settings, informing them of the project and of the possibility and need for their own participation. Participants will be asked to contact researchers in case they are interested and wish to volunteer. Research participants will be selected equitably; there will be no unequal relationships between persons involved in the recruitment and the potential participants, in particular young people of the participating universities. We will ask all involved researchers to ascertain that there is no conflict of interests and that they are not under any, even perceived, pressure to obtain certain results or to recruit specific persons or groups of persons.

- Authorisations and approvals

Prior to fieldwork we will also establish a research protocol that clearly defines – for each region/country studied – permission requirements and ascertain that all necessary conditions are met to guarantee high ethical standards. Wherever necessary, we will, *first*, seek approval for conducting the research from the jurisdictional authorities; *second*, in compliance with national legislations, all authorisations requirements will be met according to specific national directives and laws prior to fieldwork phase; *third*, approval will be sought from national/regional/institutional ethics advisers.

All copies of necessary authorisations, notifications of approval from national/regional/institutional ethics advisers will be submitted to REA prior to start of the field work research and by month 9.

- Informed consent

No minors will be included in the research. The ability to give informed consent will be a mandatory inclusion criterion. Potential participants who are unable to give informed consent will be excluded from the study.

Researchers will distribute letters to young adults informing and requesting their permission for being involved in the research. This letter will outline the aims of the research, its intended purposes, a guarantee for confidentiality and anonymity, an explanation how data will be processed and stored, the duration and extent of involvement, an explanation regarding incidental findings (see below), and the right to withdraw from the research at any time, even after they have been interviewed. It will also explain why it is important for the research that their opinions are represented and young adults will be made fully aware of their rights and the nature of informed consent in appropriate ways. The information letter will include contact details, where study participants could request further information, or ask for their data to be deleted from the study. All participants will then be asked to sign a tear-off form acknowledging that they understand their rights and stating whether or not they give their informed consent for participation in the research as well as whether they would be interested in being involved in the subsequent case studies.

At the beginning of each interview researchers will briefly re-state the voluntariness and confidentiality of the participation and their right to withdraw at any stage, prior, during and after the interview without any negative implications.

The process of obtaining informed consent will be an *ongoing* process and at subsequent stages, those students who volunteer for the subsequent research activities will be constantly reminded of the voluntary nature of participation and their right to withdraw any stage, in particular if they should show signs of distress (see below).

All copies of informational material, letters, and forms used for the collection of informed consent will be submitted to REA prior to start of the field work research and by month 9.

- Incidental findings

Due to the nature and focus of the research, we envisage no need for an explicit policy on incidental findings. However, findings will be recurrently screened and reflected upon as to their potential implications. We will communicate clearly prior to starting interviews that we may disclose information pertaining serious illegal behaviour (dealing with drugs, sexual abuse, violence against persons, terrorism, etc.) to the relevant authorities.

- Measures taken to prevent the risk of enhancing vulnerability

We are aware that the interviews may touch on sensitive topics (perceived failure to start a professional career, problems in school, problems in the family), which might induce stress, anxiety or even a feeling of humiliation. Therefore, all researchers involved in fieldwork must obtain prior training. This training covers ethical conduct, good practice and national legislation. Interviewers must prove their practical ability to avoid negative feelings as far as possible (a) by communicating very clearly that the study does not contain judgmental elements and that the content of each interview will be fully anonymized, (b) by creating a relaxed and protected atmosphere for the study participant, and (c) by stopping an interview when the study participant shows signs of distress or aggression.

As discussed above, in terms of a reflective and careful practice of language use and representation of our research participants an important concern is to avoid practices of othering, stereotypization, stigmatization and the like, thus preventing the reproduction or exacerbation of inequalities and discrimination.

- Protection of personal data

All procedures will comply both with national and European legislation. Particular attention will be given to

a) *Collection*: The anonymization of personal data is applied from early in the process, for instance, interview transcripts/data and personal information are separated directly at collection. We will ensure that data is kept securely and that any publication, including publications on the internet, neither directly nor indirectly leads to a breach of agreed protection of anonymity.
b) *Storage and protection*: Data will be stored in secure servers at the partner universities; access to data is provided only to authorized project users. All persons with access to data are registered users, i.e., they will have a format authorization with unique user-ID; there will also be a regular review of user accounts, access rights allocated on 'need-to-have'-basis and revocation if necessary. All persons will be briefed on a clear work environment practice, i.e., that critical information is protected when not in use, no loose documents on employees desks', no reference to documents on user's desktop (PC), etc.
c) *Conservation and destruction*: After the end of the project, or at any time on request of a participant, all personal data no longer required will be permanently deleted, mobile data devices formatted and original data destroyed (shredded).

***Work Packages 7 & 8***

WP7 (*Regional/Local Caste Studies*) and WP8 (*Comparative Analysis and Reporting)* involve primarily analytical desk research. In the research process, this means the bringing together of research findings from previous WPs, thus requiring further consideration and attention to the ethical issues observed in the project. So far we envisage no serious risks in terms of ethics issues and data protection, but research activities will be recurrently screened and reflected upon as to their potential ethical implications or risks. As far as the case studies (WP7) are concerned, their selection (both in terms of 'good practices' and 'contrasting cases') will be carried out avoiding potential conflicts of interests related to the formal and informal researchers' networks.

***Work Package 9 & 10***

WP9 (*Policy Roundtables*) and WP10 (*Ethics and Dissemination*) prepare and implement communication and dissemination activities in each participating country. As such, these WPs are strongly related with exchanging with specific groups – young people, researchers, general public, and decision-makers – at all levels and aims at securing a as wide as possible representation of the different stake-holders in a process of dialogic communication.

Surfacing at this point are issues of power relations and voice since the individuals/groups involved have different competences and possibilities of entering the conversation and advocating their interests. This refers for instance to the composition of roundtables, forms of representing groups, the level of accessibility of language used in the different communications and publications, etc. Ethical concerns here refer to balancing and countering imbalances in order to secure a fair, democratic and open dialogue about the topics and issues of the project, in particular safeguarding the interests and welfare of the participants in vulnerable positions.

## 4. Informational Material and Forms for the Collection of Informed Consent

In order to secure free and informed consent from participants, informational material and forms for the collection and documentation of informed consent will be prepared and submitted to REA prior to begin of data collection (month 9).

- Information letters

These letters will address young adults in educational/professional settings to inform them of the project and of the possibility and need for their own participation. They will include:

- a brief outline of the aims of the research and its intended purposes;
- the duration and extent of involvement;
- information on their rights and the nature of informed consent. In particular, the right to withdraw from the research at any time, even after they have been interviewed;
- a guarantee for confidentiality and anonymity and an explanation how data will be processed and stored;
- an explanation regarding incidental findings;
- the importance for the research that their opinions are represented; and
- contact details, where study participants could request further information, or ask for their data to be deleted from the study after participation.

While balancing the quantity and quality of information provided, the letters will be written in the language of the prospective respondents and in a style that makes understanding easy, avoiding technical language or jargon. Prospective participants will be given opportunity to go away and think about their decision to participate or not, which includes seeking further independent information.

- Forms for the collection and documentation of informed consent

All participants will then be asked to sign a tear-off form will include:

- acknowledgement of understanding of their rights;
- an explicit and unambiguous statement of informed consent for participation in the research;
- an expression of interest in being involved in the subsequent phases of the project.

The tear-off forms used to collect informed consent will be retained in a locked cabinet and will only be used to identify potential respondents for the subsequent phases. For individual interviews or focus groups, pseudonyms will be used to anonymise responses and care will be taken that the level of detail provided in direct quotes cannot inadvertently identify respondents. Participants will be offered the opportunity to choose their own pseudonyms.

## 5. Timeline for Review of Activities and Update of the Working Paper on Ethics

The Working Paper is a working document to guide and monitor research activities and will be continuously revisited, reviewed and developed further along the research and dissemination activities during the full lifetime of the project. Specifically, based on ongoing research and preliminary results from WPs the document will be periodically updated according to the following plan:

| **Review and update number** | **Related to WP or activity** | **Estimated time** |
|---|---|---|
| 1 | Mapping of policy field completed (WP3); | Month 6 |
| 2 | Preparation for data collection individual level (WP5) | Month 11 |
| 3 | Quantitative Data Analysis completed (WP4); implementation of fieldwork (WP5) | Month 21 |
| 4 | Preparation for Policy Roundtables (WP9) | Month 26 |

## 6. References

Council of Europe (2010). European convention on human rights. http://www.echr.coe.int/Documents/Convention_ENG.pdf [Accessed June 21, 2016].

Council of Europe (1981). Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (Data Protection Directive and Convention 108), online at: https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=0900001680078b37 [accessed June 10, 2016].

EC (2010). European Textbook on Ethics in Research. Online: http://ec.europa.eu/research/science-society/document_library/pdf_06/textbook-on-ethics-report_en.pdf [Accessed June 10, 2016].

EC (2013a). Ethics for Researchers. Facilitating Research Excellence in FP7. Online at: http://ec.europa.eu/research/participants/data/ref/fp7/89888/ethics-for-researchers_en.pdf [Accessed Feb. 04, 2016].

EC (2013b). Gendered Innovations. How Gender Analysis Contributes to Research. Online: http://ec.europa.eu/research/science-society/document_library/pdf_06/gendered_innovations.pdf [Accessed May 07, 2015].

EC (2015). Guidance. How to complete your ethics self-assessment. Version 4.01, 8 October 2015. Online at: http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/ethics/h2020_hi_ethics-self-assess_en.pdf [[Accessed June 10, 2016].

European Parliament (2000). Charter of Fundamental Rights of the European Union (2000/C 364/01). Online at: http://www.europarl.europa.eu/charter/pdf/text_en.pdf [Accessed Feb. 04, 2016].

European Union Agency for Fundamental Rights (2014). Handbook on European data protection law. Luxembourg: Publications Office of the European Union.

European Union Agency for Fundamental Rights (2014). Handbook on European Data Protection Law: Luxembourg: Publications Office of the European Union. Online: http://www.echr.coe.int/Documents/Handbook_data_protection_ENG.pdf [Accessed June. 10, 2016].

Fenstermaker, S. & West, C. (1995). Doing Difference, *Gender & Society,* 9, pp. 8-37

Habermas, J. (1990). Discourse ethics: notes on a program of philosophical justification. In Benhabib, S. & Dallmayr, F. (Eds.), *The communicative ethics controversy*. Cambridge, MS.: MIT Press, pp. 11-77.

Iacovou, M., Kaminska, O & Levy, H (2011). Using EU-SILC data for cross-national analysis: strengths, problems and recommendations. Online at: https://www.iser.essex.ac.uk/research/publications/working-papers/iser/2012-03.pdf [Accessed June 10, 2016].

ISO (International Organization for Standardization) (2013). *Information technology – Security techniques – Information security management systems – Requirements*. *ISO/IEC 27001.* Online: http://www.iso.org/iso/home/store/catalogue_ics/catalogue_detail_ics.htm?csnumber=54534 [Accessed June. 10, 2016].

Rachels, J. & Rachels, S. (2009). *The elements of moral philosophy*. New York: McGraw-Hill.

Spivak, G. C. (1985). The Rani of Sirmur: An Essay in Reading the Archives. *History and Theory: Studies in the Philosophy of History*, 24(3): 247-272.

Stauber, Barbara & Parreira do Amaral, Marcelo. (2015). Access to and Accessibility of Education: An Analytic and Conceptual Approach to a Multidimensional Issue. European Education, 47:1, 11-25

The Nuremberg Code (1947). Online at: http://www.cirp.org/library/ethics/nuremberg/ [Accessed June 10, 2016].

UN (1948). Universal Declaration of Human Rights. Online: http://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf [Accessed June 21, 2016].

UNDP (United Nations Development Programme) (2014). *Human Development Report 2014. Sustaining human progress: Reducing vulnerability and building resilience.* New York: UNDP.

UN-OHCHR (United Nations Office of the High Commissioner) (1966). International Covenant on Civil and Political Rights. Online: http://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx [Accessed June 10, 2016].

World Media Association. (2008). The Declaration of Helsinki. (DoH/Oct 2008). Online: http://www.wma.net/en/30publications/10policies/b3/17c.pdf [Accessed June. 21, 2016].

**Annex – National Data Protection Requirements**

In this annex you find the references to the national data protection requirements and other valid Codes of Conduct in Research of all countries and institutions participating in the YOUNG_ADULLLT project as they will be adhered to.

**Austria**

Federal Data Protection Act (Bundesgesetz über den Schutz personenbezogener Daten; Datenschutzgesetz 2000) (DSG 2000): http://www.ris.bka.gv.at/GeltendeFassung/Bundesnormen/10001597/DSG%202000%2c%20Fassung%20vom%2009.06.2016.pdf [retrieved June 9, 2016].

Code of Conduct of the University of Vienna (2013): http://phil-kult.univie.ac.at/uploads/media/Code_of_Conduct_english_01.pdf [retrieved June 9, 2016].

**Bulgaria**

Law for Protection of Personal Data (PDPL) (ЗАКОН ЗА ЗАЩИТА НА ЛИЧНИТЕ ДАННИ) (2011): http://store.aip-bg.org/laws/PDPA.pdf [official English version retrieved June 9, 2016].

**Croatia**

Croatian Data Protection Act (Zakon o zaštiti osobnih podataka) (2003): http://www.zakon.hr/z/220/Zakon-o-za%C5%A1titi-osobnih-podataka [retrieved June 10, 2016].

National Ethical Code of Scientific Research (Etički Kodeks Odbora za Etiku u Znanosti I Visokom Obrazovanju) (2015): http://www.izor.hr/c/document_library/get_file?p_l_id=60825&folderId=60844&name=DLFE-1701.pdf [retrieved June 10, 2016].

Ethical code of Zagreb University (Etički Kodeks Sveučilišta u Zagrebu) (2007): https://www.hrstud.unizg.hr/images/50014335/Eticki_kodeks-1.pdf [retrieved June 10, 2016].

**Finland**

Finnish Data Protection Act (Henkilötietolaki) (1999): http://www.finlex.fi/fi/laki/ajantasa/1999/19990523 [retrieved June 14, 2016].

Responsible conduct of research and procedures for handling allegations of misconduct in Finland (Hyvä tieteellinen käytäntö ja sen loukkausepäilyjen käsitteleminen Suomess) Guidelines of the Finnish Advisory Board on Research Integrity (2012): http://www.tenk.fi/sites/tenk.fi/files/HTK_ohje_2012.pdf [retrieved June 9, 2016].

Ethical principles of research in the humanities and social and behavioural sciences and proposals for ethical review of the National Advisory Board on Research Ethics (2009): http://www.tenk.fi/sites/tenk.fi/files/ethicalprinciples.pdf [retrieved June 10, 2016].

**Germany**

Federal Data Protection Act (Bundesdatenschutzgesetz) (BDSG 2015): https://www.gesetze-im-internet.de/bundesrecht/bdsg_1990/gesamt.pdf [retrieved May 24, 2016].

Data Protection Act – State of North Rhine-Westphalia (Landesdatenschutzgesetz Nordrhein-Westfalen) (LDSG NRW 2016): https://recht.nrw.de/lmi/owa/br_bes_text?anw_nr=2&gld_nr=2&ugl_nr=20061&bes_id=4908&aufgehoben=N&menu=1&sg=0 [retrieved May 24, 2016].

Data Protection Act – State of Hesse (Landesdatenschutzgesetz Hessen) (LDSG Hesse 2011): https://www.datenschutz.hessen.de/datenschgesetz_infos.htm [retrieved May 24, 2016].

Data Protection Act – State of Baden-Wuerttemberg (Landesdatenschutzgesetz Baden-Wuerttemberg) (LDSG BW 2015): http://www.baden-wuerttemberg.datenschutz.de/wp-content/uploads/2013/02/LDSG_2016_gueltig_-ab_1.1.2016.pdf [retrieved May 24, 2016].

Data Protection Act – State of Bremen (Landesdatenschutzgesetz Bremen) (LDSG Bremen 2003): http://www.ess-koeln.de/dokumente/160/151010083939Bremen.pdf [retrieved May 25, 2016].

**Italy**

Data Protection Code - Legislative Decree no. 196/2003 (Codice in Materia di Protezione dei Dati Personali) (2003): http://194.242.234.211/documents/10160/2012405/Personal+Data+Protection+Code+-+Legislat.+Decree+no.196+of+30+June+2003.pdf [retrieved June 14, 2016].

Code of conduct and professional practice applying to processing of personal data for statistical and scientific purposes (Codice di deontologia e di buona condotta per i trattamenti di dati personali per scopi statistici e scientifici) (2004): http://www.garanteprivacy.it/web/guest/home/docweb/-/docweb-display/docweb/1115480 [retrieved June 14, 2016].

General Authorisation to Process Personal Data for Scientific Research Purposes – Authorisation no. 9/2014 (Autorizzazione generale al trattamento dei dati personali effettuato per scopi di ricerca scientifica – Autorizzazione n. 9/2014) (2014): http://www.garanteprivacy.it/web/guest/home/docweb/-/docweb-display/docweb/3786078 [retrieved June 14, 2016].

Authorisation to Transfer Personal Data from the State's Territory to Third Countries (Trasferimento dei dati personali all'estero - Autorizzazione al trasferimento di dati personali dal territorio dello Stato verso paesi terzi) (2005): http://www.garanteprivacy.it/web/guest/home/docweb/-/docweb-display/docweb/1214121 [retrieved June 14, 2016].

Regulation governing the processing, communication, and disclosure of personal data (Regolamento in materia di trattamento, comunicazione, e diffusione dei dati personali - D.R. n. 198 del 11.07.2001) (2001): https://unige.it/regolamenti/org/privacy.html [retrieved June 14, 2016].

Regulation for the treatment of sensitive and judicial data (Regolamento per il trattamento dei dati sensibili e giudiziari in attuazione del D.lgs. 196/2003 - D.R. n. 165 del 12.4.2006) (2006): https://unige.it/regolamenti/org/dati_sensibili.html [retrieved June 14, 2016].

**Portugal**

Law on Personal Data Protection (Lei n.º 67/98, de 26 de Outubro) (1998): https://www.cnpd.pt/bin/legis/nacional/LPD.pdf [retrieved June 9, 2016].

Ethical Chart of the Portuguese Society of Educational Sciences (Instrumento de Regulação Ètico – Deontológica – Carta Ètica) (2014): http://www.spce.org.pt/regulacaoeticodeontologia.html [retrieved June 9, 2016].

Deontological Code of the Portuguese Sociological Association (Código Deontológico - Associação Portuguesa de Sociologia) (1992): http://www.aps.pt/cms/files/conteudos/CD_APS.pdf?phpMyAdmin=af2d125c3425354aa5b3cd77ef98e683 [retrieved June 9, 2016].

**Spain**

Framework Act 15/1999, on December 13th, on Private Data Protection (Ley Orgánica 15/1999, de 13 de diciembre, de Protección de Datos de Carácter Personal) (LOPD 1999): http://www.boe.es/boe/dias/1999/12/14/pdfs/A43088-43099.pdf [retrieved June 9, 2016].

Royal Decree 1720/2007, of 21 December approving the Regulation implementing Organic Law 15/1999, of 13 December, on the Protection of Personal Data (Real Decreto 720/2007, de 21 de diciembre, por el que se aprueba el Reglamento de desarrollo de la Ley Orgánica 15/1999, de 13 de diciembre, de protección de datos de carácter personal) (RDLOPD 2007): https://www.boe.es/boe/dias/2008/01/19/pdfs/A04103-04136.pdf [retrieved June 09, 2016].

Decree No. 434/2015 of 29 of September through which the Statutes of the Transparency and Data Protection Council are approved (Decreto 434/2015, de 29 de septiembre, por el que se aprueban los estatutos del consejo de transparencia y Protección de Datos de Andalucía)(BOJA 2015): http://www.juntadeandalucia.es/boja/2015/193/BOJA15-193-00009-16181-01_00077146.pdf [retrieved June 09, 2016].

Regulation of the University of Granada on the Protection of Personal Data (Resolución de 13 de diciembre de 2012, de la Universidad de Granada, por la que se ordena la publicación del Reglamento de Protección de Datos de Carácter Personal) (BOJA 2012): http://www.juntadeandalucia.es/eboja/2012/248/BOJA12-248-00027-20248-01_00018401.pdf [retrieved June 09, 2016].

Code of Good Practice in Research of the Autonomous University of Barcelona (Buenas prácticas en la investigación) (2013): http://www.uab.cat/web/research/itineraries/tools-resources-for-scientific-research/good-research-practices-1345667278314.html [retrieved June 14, 2016].

**United Kingdom**

Data Protection Act (1998): http://www.legislation.gov.uk/ukpga/1998/29/pdfs/ukpga_19980029_en.pdf [retrieved June 9, 2016].