



D1.10 SECOND ETHICAL REPORT

Project Acronym	DiDIY	
Project Name	Digital Do It Yourself	
Grant Agreement no.	644344	
Start date of the project	01/01/2015	
End date of the project	30/06/2017	
Work Package producing the document	WP1 – Project Management	
WP Lead Partner	LIUC	
Other Partner(s) involved	all	
Deliverable identifier	D1.10	
Deliverable lead beneficiary	LIUC	
Due date	M30 (June 2017)	
Date of delivery	30/06/2017	
Version	1.0	
Author(s)	Ethics Advisor; LIUC	
License	Creative Commons Attribution ShareAlike 4.0	
Classification	PUBLIC	
Document Status	APPROVED	
This project has received funding from the European Union's Horizon 2020 research and		
innovation programme under grant agreement No 644244		

innovation programme under grant agreement No 644344.

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Disclaimer

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Executive summary

Deliverable D1.10, Second Ethical Report, defines, as the previous analogous deliverable, D1.9, key ethical issues concerning research activities as identified and established according to EU and national directives, for the final part of the DiDIY Project. Like D1.9, this ethical report is focused on the procedures adopted by the beneficiaries to carry out the action in compliance with:

- ethical principles (including the highest standards of research integrity as set out, for instance, in the European Code of Conduct for Research Integrity and including, in particular, avoiding fabrication, falsification, plagiarism or other research misconduct);
- applicable international, EU and national law.

Revision history			
Version	Date	Created / modified by	Comments
0.0	09/06/17	Ethics Advisor	First, incomplete draft, for MO internal circulation.
0.1	16/06/17	MO – LIUC	Layout revision.
0.2	28/06/17	LIUC	Fixes.
1.0	30/06/17	LIUC	Approved version, submitted to the EC Participant Portal.

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Introduction

Purpose and state

This deliverable provides information on key ethical issues concerning research activities as identified and established according to EU and national directives, relating to the second 15 months of the Project. It is focused on the procedures adopted by the beneficiaries to carry out the action in compliance with (i) ethical principles (including the highest standards of research integrity – as set out, e.g., in the European Code of Conduct for Research Integrity – and including, in particular, avoiding fabrication, falsification, plagiarism or other research misconduct); (ii) applicable international, EU, and national law.

Terms and acronyms

EC	European Commission
REA	Research Executive Agency
GA	Grant Agreement
CA	Consortium Agreement
SB	Steering Board
MO	Management Office
WP	Work Package
Н	Humans
POPD	Protection of Personal Data
OEI	Other Ethics Issues
ABACUS	AB.ACUS SRL – Member
FKI	STICHTING FREE KNOWLEDGE INSTITUTE – Member
AC	AMERIKANIKO KOLLEGIO ANATOLIA – Member
POLIMI	POLITECNICO DI MILANO – Member
MMU	THE MANCHESTER METROPOLITAN UNIVERSITY – Member
UoW	THE UNIVERSITY OF WESTMINSTER LBG – Member
LIUC	UNIVERSITA' CARLO CATTANEO LIUC – Coordinator

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1. Description

Also in this second and final report, in accordance with the information related to the Ethics requirements of DiDIY project and the above mentioned principles, regarding the periodic ethical report, it is appropriate to set a preliminary analysis about the scope and the subject of this special activity. Firstly, it should be emphasized that the general relevant principles are those of ethics, and, on the other hand, those following the application of international, European and National laws. Secondly, in the DiDIY Grant Agreement, which regulates and defines the project activity, are listed a series of Ethics Requirements that represent as many significant operative criteria.

Conventional norms, that can be found in the regulation of the project and that deal with these ethics requirements, define the recruitment procedures of participants and the criteria on the basis of which such recruitment refers to. The same conventional norms recall the informed consent procedures, that are mandatory to permit participants to answer the questionnaire with the requested data. These procedures should necessarily refer to the purpose of the research, the duration of the research, the procedures and modalities of participation of the recruited persons, with the prediction of the possible risks and, above all, the need to indicate data protection procedures.

Besides that, it seems necessary to check whether there is a close and ethically relevant relationship with the "right to be forgotten" for the data collected from each participant. Moreover, from the ethical point of view, the verification of regularity and correctness of the procedures adopted will necessarily focus on the examination of any problems resulting by the automatic identifiability of the participants, on the basis of gender, religious or political beliefs, sexual orientations.

It should also be emphasized that the aspects related to ethics, within the audited project, were divided according to a scheme which has identified 12 categories that compose what we briefly described as ethical environment or scope of ethical relevance.

Specifically, the criteria on the basis of which the ethical checks must be carried out and formulated are focused on:

- 1. risks evaluation, from the ethical point of view, which can be unexpectedly generated and, therefore, not predictable at the beginning of the research;
- 2. evaluation and analysis of the procedures and criteria to be used to identify and recruit research participants;
- 3. evaluation of detailed information to be provided in relation to the informed consent procedures;
- 4. evaluation of the detailed information provided about the procedures used for data collection, for data storage, for data protection, for the eventual elimination of data collected, always checking that the data processing complies to the national legislation of the individual countries in which the data is collected and processed, together with the European union legislation;
- 5. verification of the existence of the application of elements of identification, directed to verify the environment where the data were collected, such as time, date and place of data collection, the type of module used, and an indication of the subdivision of the data categories. Specifically, it must be verified whether the candidates were made be aware that a recent jurisprudence from the European Court of Justice introduced "a right to be forgotten" which implies that identifiers must in time be deleted. Therefore, depending by certain conditions, it should be considered that those who provided data can require the application of this new law;

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- 6. adoption of informed consent procedures and on their actual implementation;
- 7. verification of the communication of the details on incidental findings policy related to sensitive data, such as medical and psychiatric, that are not related with the purpose of research;
- 8. presence of specific authorization given through the informed consent procedures to collect and process personal data;
- 9. anticipation of the submission to the REA of the authorizations, as well as approvals for the collection of personal data from the competent officials for the protection of data within the University as well, although only as an eventuality, from the National Authority for the protection of privacy and of personal information;
- 10. anticipation of the submission to the REA of the authorizations of the approval of the competent authorities, which concern individual ethical issues different from the collection of personal data;
- 11. designation of an external independent Ethics Advisor appointed to oversee the potential ethical concerns involved in the research. The Ethics Advisor will prepare and submit to the REA a periodic report together with the financial accounts;
- 12. adoption of models for the collection of informed consent as well as information sheets that should have a language and terms that are easily understood by the participants in the research.

Starting from the examination of these 12 specific features, it is clear that the ethics report will follow three basic guidelines: the first one will focus on general ethical issues, other than those involved in the specific research; the second one will focus on the individual correlation, on the one hand, of the operators who have carried out research activities and, on the other hand, of the recruited participants, so as to identify a unified criterion that concerns the integrity of the subject under the ethical aspect. In this specific case, we should necessarily point out that individual specificities must necessarily be related to the kind of research and to the content that such research involves, because the respect of ethical criteria, especially as specified above, should be appropriate to the research itself, so that, in case of absence of potential risks – such as in some aspects of the program that we are checking – there is only the need to specify that those risks and their potential occurrence are absent. Therefore, on the basis of what we have described above, examining modalities and criteria adopted in the DiDIY project, it should be emphasized that among all the partners of the consortium involved and in the program (University of Westminster, Manchester Metropolitan University, Amerikaniko Kollegio Anatolia, Politecnico di Milano, Stiching Free Knowledge Institute, Abacus srl, Università Carlo Cattaneo – LIUC), only five partners conducted activities for data acquisition and, therefore, it is necessary to proceed with the ethics verification only in relation to such partners.

It is necessary to preliminary point out that national laws involved, to which some of the criteria refer to, are those of the Italian Republic, the Kingdom of the Netherlands and the United Kingdom since, as we said, the other participants did not perform any sensible activities. We can, therefore, conclude that, with respect to the project partners, who have not carried out any recruitment and data collection activities, there will be no verification of ethical nature.

The report must necessarily take into consideration, individually, for each project partner, the specific categories of ethical nature mentioned above, in order to produce a number of reports that it is the same to the formal list of the necessary requirements.

Additional specification, of procedural issue, concerns the way by which the activities, carried out by individual partners, have been examined. Was sent, to each of the partners, a questionnaire which

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contains the information and, therefore, contains the essential questions to set up the ethical framework as described above.

This method of investigation, also for this second report, within the object of the research program, whose ethical context we are analysing, appears to be coherent with the general indications, as well as coherent with the advice activity and ethical coaching.

The questions, the partners have had to formally reply, entered on the form, have concerned the following general aspects:

- if direct activities to the acquisition of data have been realized;
- the procedures and criteria for recruitment;
- the deal of the data collected.

The questionnaire form (and the questions contained) was focused on the elements and specific criteria, listed above, precisely reproducing the ethics investigation layout required for the program.

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2. H – Requirements No. 01

Ethics Requirement Description

Details on the procedures and criteria that will be used to identify/recruit research participants must be provided.

Verification of the relevant activities carried out by partner FKI

According to the responses to the questionnaire mentioned in section 1, it emerges that the identification procedures and criteria, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases, also in this second part of the activity.

Verification of the activities carried out by partner LIUC

According to the responses to the questionnaire mentioned in section 1, it emerges that the identification procedures and criteria, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases also in this second part of the activity.

Verification of the activities carried out by partner ABACUS

According to the responses to the questionnaire mentioned in section 1, it emerges that the identification procedures and criteria, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases also in this second part of the activity.

Verification of the relevant activities carried out by partner POLIMI

According to the responses to the questionnaire mentioned in section 1, it emerges that the identification procedures and criteria, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases.

Verification of the relevant activities carried out by partner UOW

According to the responses to the questionnaire mentioned in section 1, it emerges that the identification procedures and criteria, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases, in this second part of the activity.

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3. H – Requirements No. 02

Ethics Requirement Description

Detailed information must be provided on the informed consent procedures that will be implemented.

Verification of the activities carried out by partner FKI

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases also in this second part of the activity.

Verification of the activities carried out by partner LIUC

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases also in this second part of the activity.

Verification of the activities carried out by partner ABACUS

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases also in this second part of the activity.

Verification of the activities carried out by partner POLIMI

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases.

Verification of the activities carried out by partner UOW

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases in this second part of the activity.

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4. H – Requirements No. 03

Ethics Requirement Description

Details on incidental findings policy must be provided.

Verification of the activities carried out by partner FKI

According to the responses to the questionnaire mentioned in section 1, it emerges that the policy, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner LIUC

According to the responses to the questionnaire mentioned in section 1, it emerges that the policy, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner ABACUS

According to the responses to the questionnaire mentioned in section 1, it emerges that the policy, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner POLIMI

According to the responses to the questionnaire mentioned in section 1, it emerges that the policy, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities*.

Verification of the activities carried out by UOW

According to the responses to the questionnaire mentioned in section 1, it emerges that the policy, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* in this second part of the activity.

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5. POPD – Requirements No. 04

Ethics Requirement Description

Detailed information must be provided on the procedures that will be implemented for data collection, storage, protection, retention and destruction and confirmation that they comply with national and EU legislation.

Verification of the activities carried out by partner FKI

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, although not specifically considered, partially are provided in the previous activities.

Verification of the activities carried out by LIUC

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, *are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner ABACUS

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, *are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner POLIMI

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, although not specifically considered, partially are provided in the previous activities.

Verification of the activities carried out by UOW

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, *are provided in the previous activities* in this second part of the activity.

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6. POPD – Requirements No. 05

Ethics Requirement Description

A number of identifiers (not only related to the identify of the participants but also as regard to the environment in which the data was collected: date of collection, format, hour, location, metadata sets, ...). These aspects must be considered and adequately documented by the applicants. More specifically, the applicants must be made aware that a recent jurisprudence from the European Court of Justice introduced "a right to be forgotten" which implies that identifiers must in time be deleted. The applicants must provide a proper process in order to consider this novel right and subsequent obligations.

Verification of the activities carried out by FKI

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner LIUC

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, *are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner ABACUS

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner POLIMI

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, although not specifically considered, partially are provided in the previous activities, because POLIMI did not collect personal data during the workshops.

Verification of the activities carried out by partner UOW

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, *are provided in the previous activities* in this second part of the activity.

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7. POPD – Requirements No. 06

Ethics Requirement Description

Detailed information must be provided on the informed consent procedures that will be implemented.

Verification of the activities carried out by partner FKI

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner LIUC

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, *are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner ABACUS

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, appear correct and coherent with the procedures expected in similar cases also in this second part of the activity.

Verification of the activities carried out by partner POLIMI

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, appear correct and coherent with the procedures expected in similar cases also in this second part of the activity also in this second part of the activity.

Verification of the activities carried out by partner UoW

According to the responses to the questionnaire mentioned in section 1, it emerges that the information procedures, *are provided in the previous activities* in this second part of the activity.

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8. POPD – Requirements No. 07

Ethics Requirement Description

Justification must be given in case of collection and/or processing of personal sensitive data.

Verification of the activities carried out by partner FKI

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner LIUC

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases also in this second part of the activity.

Verification of the activities carried out by partner ABACUS

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases also in this second part of the activity.

Verification of the activities carried out by partner POLIMI

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, partially are provided in the previous activities, because POLIMI did not collect personal data during the workshops.

Verification of the activities carried out by partner UOW

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, appear correct and coherent with the procedures expected in similar cases in this second part of the activity.

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9. POPD – Requirements No. 08

Ethics Requirement Description

Copies of ethical approvals for the collection of personal data by the competent University Data Protection Officer / National Data Protection authority must be submitted to the REA.

Verification of the activities carried out by FKI

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner LIUC

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner ABACUS

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner POLIMI

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity, even POLIMI did not collect personal data during the workshops.

Verification of the activities carried out by UOW

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* in this second part of the activity.

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10. OEI – Requirements No. 09

Ethics Requirement Description

The applicants must assess mission/function creep risks, document and mitigate them.

Verification of the activities carried out by partner FKI

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures of data collection, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities*, generally reflecting the risks mentioned above, appear correct and coherent with the procedures expected in similar cases, also in this second part of the activity.

Verification of the activities carried out by partner LIUC

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures of data collection, in reference to the risks mentioned above, *although not specifically considered, partially are provided in the previous activities*, reflecting the risks mentioned above, appear correct and coherent with the procedures expected in similar cases also in this second part of the activity.

Verification of the activities carried out by partner Abacus

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures of data collection, in reference to the risks mentioned above, <u>although not specifically considered</u>, <u>partially are provided in the previous activities</u>, reflecting the risks mentioned above, appear correct and coherent with the procedures expected in similar cases also in this second part of the activity.

Verification of the activities carried out by partner POLIMI

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures of data collection, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities*, reflecting the risks mentioned above, appear correct and coherent with the procedures expected in similar cases.

Verification of the activities carried out by partner UOW

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures of data collection, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities*, generally reflecting the risks mentioned above, appear correct and coherent with the procedures expected in similar cases, in this second part of the activity.

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11. OEI – Requirements No. 10

Ethics Requirement Description

Copies of ethical approvals by the competent authorities must be submitted to the REA.

Verification of the activities carried out by partner FKI

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner LIUC

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner ABACUS

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* also in this second part of the activity.

Verification of the activities carried out by partner POLIMI

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities*.

Verification of the activities carried out by partner UOW

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities* in this second part of the activity.

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12. OEI – Requirements No. 11

Ethics Requirement Description

An external independent Ethics Advisor must be appointed to oversee the ethical concerns involved in this research. A report by an Ethics Advisor must be submitted to the REA with the financial reports.

Verification of the activities carried out by the consortium

The procedure of identification, appointment, and planning of the activities of the Ethics Advisor is coherent with the ethical principles of the Project also in this second part of the activity.

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13. OEI – Requirements No. 12

Ethics Requirement Description

Templates must be provided for Informed Consent Forms and Information Sheets (in language and terms understandable to the participants).

Verification of the activities carried out partner FKI

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities*; this seems an acceptable result also in this second part of the activity.

Verification of the activities carried out partner LIUC

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities*; this seems an acceptable result also in this second part of the activity.

Verification of the activities carried out partner ABACUS

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities*; this seems an acceptable result also in this second part of the activity.

Verification of the activities carried out by partner POLIMI

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, *although not specifically considered*, *partially are provided in the previous activities*; this seems an acceptable result.

Verification of the activities carried out by partner UOW

According to the responses to the questionnaire mentioned in section 1, it emerges that the procedures, in reference to the risks mentioned above, appear correct and coherent with the project principles in this second part of the activity.

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