



Driving Innovation in Crisis Management for European Resilience

## D95.31 – Ethical Monitoring Report 1

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<sup>1</sup> Due to technical difficulties, Hadjimatheou was only able to review the first 20 pages of the deliverable.



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## List of Acronyms

Abbreviation / acronym	Description
CCTV	Closed Circuit Television
CM	Crisis management
D	Deliverable
DoW	Description of Work
DPA	Data Protection Authority
FD	Final Demo
IT	Information Technology
JE 1 & 2	Joint Experiments 1 & 2
NENT	The Norwegian National Committee for Research Ethics in Science and Technology
SC 15	Special Clause 15 in the Ethical Guidelines of the FP7 agreements
SE 1 & 2	Subproject Experiments
SP	Sub project
WP	Workpackage

## Executive Summary

One of the main objectives of SP9 is the ethical monitoring of the project. This includes guiding the consortium in ethical issues (through deliverables, and in particular cases- bilaterally) and collecting the approvals needed for each partner. The purpose of this deliverable is to document and address key ethical issues in the first year of DRIVER, and repeat and refine some core points from previous deliverables; both to clarify some particularly important points regarding research ethics, but also to update and specify previously given guidelines. This is based on the accumulative nature of DRIVER, and the fact that the work within the project is becoming more operational and practical. Being reviewed by two members of the DRIVER ESAB, the deliverable also answers to the WP95 objectives as stated in the DRIVER DoW, namely to carry out continuous ethical monitoring in relation to the ESAB. The deliverable takes up the most pressing or challenging ethical issues as seen by SP9 and experienced by the many members of the DRIVER consortium. Although the past and on-going work with societal impact assessments and recommendations in other SP9 WP's is strongly linked to the work on research ethics in WP91 and WP95, this deliverable will focus on the methodological ethical issues, including more overarching issues that PRIO as SP- leader (in particular in WP95) have encountered and become aware of in the process of the projects first year. The input to the report is mainly derived from five different sources: 1) Ethical Monitoring Questionnaires filled out by 25 DRIVER partners required to give input as per DRIVER DoW, 2) the Societal and Ethical Advisory Board which held its first meeting in December 2014, 3) interaction in relation to the DRIVER meeting week in Ispra February 2015, in particular the workshop on research ethics and procedures held by PRIO during the General Assembly, 4) issues of ethical concerns which has become apparent to PRIO as SP9 leader (in particular as leader of WP91 "Coordination and Conceptualization of Independent monitoring" and WP95 "Ethical and Societal Advisory Board"), and 5) the information repeats and refines some core points from previous deliverables. One of the main conclusions of the report is that although there might be some challenges that need to be solved for particular experiments, no activities or experiments that include major (unacceptable) negative ethical implications are foreseen at this point. However, there *is* a risk connected to the ethical approvals, and this calls for both a clarification of the role of SP9, and a reminder to the consortium about the importance of having the appropriate ethical approvals in place.

# 1 Introduction

This report is the first of four Ethical Monitoring Reports (due in M12, M24, M36 & M48). The key ethical principles relevant for DRIVER are described in part B4 of the DRIVER DoW, and issues involved will be documented and addressed in periodic Ethical Monitoring Reports.

The basic premise for this report is the fact that research ethics fundamentally refers to the need to govern the impact (both positive and negative) that research can have on the society. The role of ethics in research has to do with both ensuring good scientific practice (i.e. researcher ethics) and safeguarding individuals and even society at large (i.e. research ethics)<sup>2</sup>. Research ethics concerns researchers, human research objects and bystanders. The DRIVER project involves the collection, processing and storage of data derived from individuals, both from members of the DRIVER consortium and individuals that are not formally part of the project. At the very core of research ethics are rules and guidelines for the participation of human subjects in research activities, which refer to the standard European Commission research ethics. The principles of the European Convention of Human Rights, the rules of the Convention of the Council of Europe for the protection of individuals with regard to the automatic processing of personal data and especially the European Directive 95/46/EC39 for the protection of personal data must be strictly upheld at all levels when addressing ethical questions and issues within DRIVER.

*Failure to uphold ethical research principles, such as obtaining the appropriate informed consent- and data protection approvals within the set timeframe, is not only exercising poor research ethics, but it is also a breach of the contractual agreement through the Special Clause 15.*

Following the previously submitted deliverables D91.3, D95.11 & D95.21, some ethical issues are especially relevant for DRIVER, and should be subject of further clarification and attention now that the project is completing its first year, and the work in the different sub- projects is increasing in complexity and becoming more operational. However, as the feedback from the Ethical Monitoring Questionnaires (hereinafter referred to as the *questionnaire*) send out to solicit feedback to this deliverable also show, a large proportion of the experimentation within DRIVER has not started by the time this report is submitted (M12).

Nonetheless, the issues described in this deliverable are issues that has been raised and discovered through various channels and mechanisms within the projects first year. The information that forms the basis for this deliverable mainly comes from five different sources that are further described below:

First, the information comes from the partners tasked in the DoW to contribute with input to this deliverable. Here, issues that are of particular relevance to the different partners have been raised, and some will be addressed specifically in the following. Partners required to give input to this document were FOI, FHG-INT, POLE, ATOS, ECORYS, MSB, JRC, FHG-IAO, ARC, DRC, ARMINES, CIES, Q4PR, FRQ, AIT, TCS, DLR, GMV, ITTI, EDI, MDA, THG, PSCE, ARTTIC & TNO. The feedback from the 25

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<sup>2</sup> The National Committee for Research Ethics in Science and Technology) (2008): Guidelines for Research Ethics in Science and Technology.

partners was solicited through the use of a questionnaire<sup>3</sup>, which was sent out to all partners on the 26<sup>th</sup> of February 2015. At least one filled out questionnaire per partner was returned to PRIO, and all the questionnaires are stored with PRIO. The final questionnaire was received on the 17<sup>th</sup> of March 2015. The questionnaire (annexed to this report) covers all the major ethics issues in part B4 of the DRIVER DoW, and contained questions on human subjects in research, ethical approvals, the interaction with SP9, potential topics for the DRIVER Societal and Ethical Advisory Board, and other ethical issues. It also contained one question tailored to potential ethical issues related to the partner's work in a specific task, WP of SP. Although not every issue can be described in detail in this deliverable (also because many of the DRIVER experiments are still pending, and detailed information cannot be given at this point), the most prominent and overarching issues and challenges are documented and addressed here. The info from the questionnaires are not addressed in particular chapters, but are embedded throughout the report. As a lot of experimentation has not yet started, the aim of the questionnaire (in addition to providing actual input to this report) was also to act as a reminder/ raise awareness of key ethical issues for future experiments.

Second, the information about ethical issues is derived from the DRIVER Ethical and Societal Advisory Board, which held its first meeting in Brussels in December 2014. The ESAB was introduced to the project, and some particular ethical issues and questions that had already appeared were raised and discussed at the meeting. Some of the key issues are reflected in this deliverable, but the details can be found in D95.11.

Third, PRIO held a workshop on research ethics and procedures during the General Assembly at the DRIVER meeting week in Ispra in February 2015, and many questions and issues were raised during and after the session. Issues of relevance to several partners are repeated and/ or discussed in this deliverable.

Forth, within WP95 lies the task of monitoring ethical approvals for the DRIVER partners. Throughout this process, it has become very clear to PRIO that although a lot of attention and effort has already been put into this task, still many questions remain unanswered and still there are misunderstandings and needs for clarifications with regards to major and minor key ethical issues (partly explained by the natural progress of the project). Thus, this deliverable seeks to document and address some of the most frequently raised issues derived e.g. from bilateral interaction between the task leader and the DRIVER partners, and also the more special cases demanding more attention as they are potentially at larger risk for having a negative impact on the DRIVER project if not upheld.

Finally, parts of the content of this deliverable are iterations and further refinements of issues from the previously submitted deliverables D91.3 and D95.21.

The structure of the deliverable is as following. The remainder of Chapter 1 explains the relation with the other deliverables on ethical issues (in particular D95.21 "Planning for the Ethical Approvals" and D91.3 "Ethical procedures, risks and safeguards"), and the scope and limitations of the first Ethical Monitoring Report.

Chapter 2 addresses and documents data protection & privacy issues, and some particular cases for DRIVER, such as the use of UAV's for data collection and the concept of "field experiments".

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<sup>3</sup> It must be noted, however, that while the partners listed in the DoW are mostly represented in this report, other partner's issues and experiences are partly represented through the other sources mentioned below.

Chapter 3 re-introduces the DRIVER experiments, and particularities relating to the inclusion of human subjects in the experiments, such as informed consent and vulnerable groups.

Chapter 4 describes the role and work of SP9 within DRIVER, what is working and what can be improved, and is largely based on the feedback from the ethical monitoring questionnaires.

Chapter 5 presents the role and activity of the DRIVER Ethical and Societal Advisory Board (ESAB) this far, and some issues suggested by the DRIVER partners to be brought to the board.

Chapter 6 further describes some suggested measures for the mitigation of risks for crisis management solutions and tools, before some final remarks to the report are made in Chapter 7.

## 1.1 The relation to D95.21 & D91.3

The sources of this report have been explained shortly above. This section aims at clarifying the relation between D95.21 “Planning for the Ethical Approvals” and D91.3 “Ethical procedures, risks and safeguards”, which also serves as backdrops for this report. Partly, there is an overlap with regards to the issues raised in the previous deliverables and this deliverable, and this overlap is not only justified, but should clearly be understood as 1) iterations and updates of the most central issues, and 2) an affirmation of the importance and relevance of the issues.

## 1.2 The scope and limitations of D95.31

Ideally, this report would allow for a comprehensive analysis of all the various ethical issues that pertains to DRIVER at this point. However, due to constraints and varying level of detail in the feedback (partly explained by relevant activities starting at a later point in the project), some key issues have been selected as the basis for this report. This does not mean that SP9 is not engaging with other ethical issues that are being raised and set forth to SP9, as these kinds of interactions are happening in parallel and in different channels (in particular through T95.2). The purpose of this report is to identify and address key ethical issues, and this includes making a distinction between smaller issues of anticipated less importance that are (or have been) easily solved between PRIO and the relevant partner through T95.2 (Special Clause 15 compliance documents), and the more overarching, general and fundamental issues which are or will most likely be of relevance to more or less the DRIVER consortium as a whole. The deliverable does not aim at summarizing all ethical issues from the first year, but rather to focus on the state of the project at this point, and to tailor the relevant information as such.



## 2 Privacy and Data Protection

### 2.1 Special Clause 15

As stated in the previous deliverables D95.11 and D91.3, in the workshop held by PRIO during the General Assembly at the DRIVER week in Ispra in February 2015, and in multiple bilateral communications with consortium partners, many research activities are and will be subject to approvals regulated by SC15, such as most interviews and experiments (among other things: workshops, field experiments and table-top exercises- including human participants).

**Special Clause 15 (SC15, FP7 List of Special Clauses) states:**

*The beneficiary(ies) shall provide the REA with a written confirmation that it has received (a) favourable opinion(s) of the relevant ethics committee(s) and, if applicable, the regulatory approval(s) of the competent national or local authority(ies) in the country in which the research is to be carried out before beginning any REA approved research requiring such opinions or approvals. The copy of the official approval from the relevant national or local ethics committees must also be provided to the REA.*

In DRIVER, it is the task of SP9 to monitor (to collect and forward to the project leadership and the Project Officer) the ethical approvals, but not to obtain or approve them on behalf of the partners. Task leaders or the data controllers (the person or entity which determine the purposes and the means of the processing of personal data), as indicated in the DoW, are ultimately responsible and accountable for obtaining the appropriate approval, on the basis of information given in both D91.3 and D95.21. A list of contact information to the different national data protection authorities within the European Union is available at: [http://ec.europa.eu/justice/data-protection/bodies/authorities/eu/index\\_en.htm](http://ec.europa.eu/justice/data-protection/bodies/authorities/eu/index_en.htm)

### 2.2 Personal data & Data Protection Approvals

In practice, to find out who controls the contents and use of personal information kept, an organisation should ask itself the following questions:

- Who decides what personal information is going to be kept?
- Who decides the use and purpose to which the information will be put?
- Who decides on the means of processing of personal data?<sup>4</sup>

If that organisation controls and is responsible for the personal data that it holds, then it is legally responsible for the data, and is defined as the data controller. If the organisation holds and processes, but does not have responsibility or control over the personal data, it is defined as the data processor.

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[http://ec.europa.eu/justice/policies/privacy/docs/international\\_transfers\\_faq/international\\_transfers\\_faq.pdf](http://ec.europa.eu/justice/policies/privacy/docs/international_transfers_faq/international_transfers_faq.pdf)

As previously stated in for example D91.3, personal data can refer to practically all forms of information that a researcher might hold. Personal data is information relating to a living individual who can be identified (a) from those data; or (b) from those data and any other information which is in the possession of, or likely to come into the possession of, anyone who may have access to it.

Data protection principles are primarily concerned with information which is (a) held, or intended to be held, on computer; or (b) held in manual records which are sufficiently structured so as to allow ready access to specific information about individuals. In other words, personal data refers to information that can lead to the identification of persons or opinions through material provided in interviews, workshops, questionnaires and that are written down and stored in handwritten notes or on computers. Information does not have to be factually correct in order to be personal data, and a person's identity can be obtained in different ways:

- Directly from identifiers such as names, addresses, postcode information, telephone numbers or pictures<sup>5 6</sup>,
- Indirectly from (cross) identifiers which, when linked with other publicly available information sources, e.g. information about workplace, occupation or characteristics like salary or age<sup>7</sup>.
- If workshops are conducted, data recorded or a participants list is kept to reimburse participants afterwards, all of this is potentially data that may identify a person.

There is reportedly a gap between what PRIO regards as personal data and what certain national DPA's regard as personal data. If this is the case, the definition from the EU Data Protection Directive (95/46/EC) should be followed. It states that "personal data" means any information relating to an identified or identifiable natural person ('Data Subject'); an identifiable person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity. It can also be noted that the definition of personal data is technology neutral, meaning that it does not matter in which way the personal data is stored, whether it is on paper, in a CCTV system (as images) or in an IT system.

According to information gathered from the questionnaire, the majority of the partners that provided input to this deliverable have already been in contact with local ethics committees or Data Protection Authorities. While the question of approvals is unclear for some partners (for example due to a late start of the activity), for most partners, the process is rather straight forward, and a decision about whether approval is necessary, easily clarified. For the more complicated cases, bilateral guidance is and has been offered by PRIO. It must be noted however, that it is the task leader's responsibility to contact e.g. the DPA (or PRIO) in such cases, but a table of anticipated tasks where approval will most likely be needed has been put together by PRIO in D95.22 (and will be updated in D95.23 due in M18).

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<sup>5</sup> Note that images are also regarded as personal data if the person may be identified. See also chapter 2.3.1 on the use of UAV's.

<sup>6</sup> <http://www.data-archive.ac.uk/create-manage/consent-ethics/anonymisation>

<sup>7</sup> *ibid*

Of the respondents of the questionnaire, roughly half reported to having used the template for seeking data protection approval which was provided by PRIO as part of D91.3 (see attachment ), and the remaining half reported not to have used the template mainly due to three reasons. 1) The template wasn't ready at the time the application was sent to the DPA, 2) the DPA in the respective country provided its own template and 3) one partner did not know that a template existed.

### 2.2.1 Do I need data protection approval?

As requested by some consortium members, a table indicating whether data protection approval is needed is presented below<sup>8</sup>. This information has been previously included in D91.3 and D95.11.

<b>Is personal data being collected?</b>		
<b>WHAT DO YOU DO?</b>	<b>IF YES</b>	<b>IF NO</b>
Do you collect directly identifiable personal data <sup>9</sup> ?	Data Protection Approval needed.	Data Protection Approval might be needed (see next question).
Do you collect indirectly identifying personal data (such as background material that might identify individuals) <sup>10</sup> ?	Data Protection Approval needed.	Data Protection Approval not needed (if "no" on previous question as well).
Will personal data be collected via online forms (direct/ indirect/ via IP-address or email address)?	Data Protection Approval needed. Note that even if only the data processor has access to the identifiable information (such as an IP-log), approval is needed.	For the collection of data through online forms to be regarded as anonymous, neither IP-address, browser information, nor information capsules etc. can be used.
Will personal data be collected through digital images or video recordings (if faces are shown, it counts as personal data)?	Data Protection Approval needed.	Data Protection Approval not needed for this particular activity, but could be needed if linked with other directly or indirectly identifying

<sup>8</sup> The table is based on information from the Norwegian Social Science Data Services (NSD). See <https://trygg.nsd.uib.no/personvern/meldeplikt/meldeplikttest>

<sup>9</sup> Such as name or national identity number. See Chapter 2.2 for definition of personal data. Note that even if the information is meant to be anonymized in the final report etc. the collection of personal data would still happen and thus the answer here should be "yes".

<sup>10</sup> A person will be indirectly identifiable if it is possible to recognize the person via a combination of background information (such as municipality or workplace / school, combined with data such as age, sex, occupation, etc.). For it to be counted as personal data, this must be recorded in combination with other information so that people can be recognized.

		personal data.
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## 2.3 Special cases & potential challenges in DRIVER

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### 2.3.1 UAV's and data protection

The DRIVER experiments are not taking place in a vacuum, but in a context of e.g. changing or lacking legislative frameworks, and the emergence of new ways and possibilities for conducting research. Methodological innovation is a *sine qua non* for the study of a changing society and its ever-changing constituent individuals and institutions, and following, new (research) methods pose new ethical problems (SRA 2003: 5). Dedicated regulations about the use of UAV's are missing in many European countries. In Norway for example, a trial period where an individual no longer need to have a license for operating an UAV is currently carried out, This means that, contrasting to earlier, as long as the UAV is not within restricted (military) area and the operator of the UAV is in proximity to it and can physically see the UAV, the use is legal. However, organisations using UAV's still have to apply for a license to do so. On a broader European level, changing regulations for the use of UAV's is foreseen in 2016<sup>11</sup>.

There is a difference between *localizing* humans and *identifying* or *tracking* humans. This also relates to the use of airborne sensor systems. The former is envisaged within DRIVER, and should adhere to some specific rules. The resolution of the imagery should only be detailed/ pixelated enough so that the viewer can determine whether the person shown is in need of assistance or not. This means for example to distinguish between humans and non-humans, not to distinguish humans with a certain trait from other humans. According to the DoW, personal identification of humans through the use of UAV's will not take place within DRIVER. Also note that while the collecting of photographic images through UAV's may be within the legal frames, the distribution and use of the images may not be. The issue of UAV's is mentioned here, but may require follow-up later in the project.

### 2.3.2 Field experiments

Informed consent is a general ethical requirement when conducting research with human beings, and the requirement arises in particular in the "field experiments" (see Chapter 3 for more information on the different DRIVER experiments and Chapter 3.3.1 of D91.3 for recommendations for informed consent). While it is still not clear exactly what such an experiment within DRIVER will include, some preliminary and general advice can already be given. Should the experiment take place in public, or where bystanders that are not part of the experiment can observe the experiment or parts of it, an extra effort should be made to get information about what is taking place out to as many relevant people as possible. This could happen in a variety of ways, for example by handing out flyers describing the activity, by announcing on local radio stations (such as University radio should the experiment happen within a University Campus), ads in the local newspaper, or notifications on info boards in the surrounding area, etc.

<sup>11</sup> <http://ec.europa.eu/transport/modes/air/news/doc/2015-03-06-drones/2015-03-06-riga-declaration-drones.pdf>

The importance of ethics in field experiments relates to different stages of the activity, before, during and after the field exercise/ experiment. Before the start of the activity it is important to prevent situations where the volunteers or the actors get a larger influence over the situations than what is desired, it is important that they are informed in advance about their expected behaviour, and relevant conditions should be clarified, such as potential allergies, claustrophobia etc. This comes in addition to giving active and voluntary consent to participating. During the activity it is important that all participants are made aware of a contact person that can be contacted during the experiment/ exercise, should any questions or concern occur. After, if it is relevant and practically possible, all volunteers and actors should have the possibility to take part in the evaluation after the exercise. If more serious effects occur, such as injuries or traumatic experiences, it is furthermore important that a responsible tactical and psychological de-brief is carried out<sup>12</sup>.

### 2.3.3 Photographic images as personal data

Photographic images of individuals may be regarded as personal data, and could thus be within the scope of the Data Protection Act. This depends on the type of image, but to err on the side of safety, a checklist for the processing of such data can look as follows<sup>13</sup>:

- The concept of function creep must still be considered for photographic images. Was the photograph taken for the purpose for which it is used?
- Is the photograph of a sensitive nature<sup>14</sup>? If so, explicit consent should be obtained.
- When photographing large groups, ask the individuals appearing on the photo verbally for permission. An individual should be given the opportunity to opt out.
- When photographing smaller groups, best practice would be to seek consent before collecting the data. Here it is important that storage, publication, deletion and purpose are specified.
- Has the subject been told how the image will be used and how it will be stored?
- Use the image only according to how the subject was told it would be used.
- If you do not have the subject's consent to process their image, what is the purpose of this image?
- Do you know how long to keep the image for, and when and how to dispose of it?

For the DRIVER experiments, both the smaller and larger activities, it seems likely that visual recordings (photo or video) will be used to collect data from the activities. The main rule is to obtain informed consent from all participants in the research activity (as with all kinds of data collection relating to human subjects), and to state clearly how the image will be stored and used. If informed consent cannot practically be obtained in advance, an effort should be made to obtain this after the data collection has taken place.

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<sup>12</sup> Løvik 2010: p. 205

<sup>13</sup>Based on a checklist issued by University of Reading:  
<http://www.reading.ac.uk/internal/imps/DataProtection/DataProtectionGuidelines/imps-d-p-photographic.aspx#checklist>

<sup>14</sup> For example showing religious beliefs, political opinions or physical or mental health.

### 2.3.4 Ethical issues particular to DRIVER

According to the feedback from the partners who gave input to this deliverable, there are a few issues that reportedly are new to DRIVER, meaning that they have not been experienced before in similar work or projects. Some issues are described below, and other and more detailed cases and challenges will, if needed, be the subject of bilateral communications between SP9 and the relevant partners.

For some partners the very issue of ethical approvals and SC15 is a new one, and for others, the experience is that research ethics has become stricter, based on previous work. What is described as the focus on “social experimentation” in DRIVER makes the work in this project different, as its research involves something more than desk- research and workshops, but the actual inclusion on people “on the ground”.

The issue of sensitive data is also new for some partners, and some experiments will reportedly include a potentially significant number of citizens with no affiliation to DRIVER, and variables in the data collected such as sex, health status, religion, and nationality, current position etc. This kind of sensitive data is often important for crisis management, and the role of sensitive data require some particular attention (see Chapter 5.2.1 for more on sensitive personal data).

Another emerging new issue for some partners is that informed consent is sometimes impossible to get in advance, for example because of the nature of the activity (meaning that it requires an element of surprise or uncertainty to be successful, not that it is deceptive or actively misleading the participants). A general rule here is that if the nature of the exercise makes it impossible to get *full* informed consent in advance, as much information as possible should be given to the participants (so that they at least are aware of their partaking in an experiment) and full informed consent should be sought after the activity. To justify withholding information, it is common to require, for example, that the utility value of the research clearly exceeds any disadvantages that may be inflicted on the subjects, the lack of alternatives and that the research should imply only minimal risk of harm to the participants.<sup>15</sup>

Finally, regarding seeking approval from Data Protection Authorities versus seeking approval from an ethical board or committee<sup>16</sup>, there has also been some confusion when it comes to where approvals should be sought. The simple answer to this is that **unless the experimentation activity involves participants acting out a scenario (what is also described as a field experiment) potentially taking place in the public, medical/ health data is collected, or the participant risk significant physical or mental harm by participating in the activity, it should be sufficient to get approval for the data collection.** Often, data protection authorities and other ethical committees are gathered in one authority and may issue both kinds of approvals, but this should be clarified in the different cases.

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<sup>15</sup> See for example Guidelines for Research Ethics in the Social Sciences, Law and the Humanities, National Committees for Research Ethics, guidelines 8 and 9

<sup>16</sup> The distinction between Ethical Boards and Data Protection Authorities is mainly that while the latter facilitates protection of individuals from violation of their right to privacy through processing of their personal data, some Ethical Boards gives advice on research ethical matters beyond ensuring respect for research subjects. In many countries (such as in Norway), guidance from ethical boards is voluntary, but should be sought if it is expected that the research project might encounter ethical challenges.

## 3 The DRIVER Experiments

In this part of the deliverable, ethical issues relating to the DRIVER experiments are addressed and documented. The experiments are at the core of the ethical issues within DRIVER and for the most part, they require adherence to data protection approvals, but also potentially other ethical approvals relating for example to activities that has implications for the public, or includes a risk for the participants.

The experiments and experiment campaigns (SE1 & SE2) carried out within the scope of DRIVER includes a very wide range of activities, and according to the DRIVER DoW, activities such as interviews or workshops are also defined as experiments. This very wide definition implies that research ethics become important in all parts and levels of the project. For example, there is a risk that applying to national ethics committees or DPA's will be more complex when a research activity is described in the application as an "experiment". Thus, it is very important that the nature of the research activity, especially with regards to the participation of human subjects, is properly described when contacting the relevant authority.

A slightly updated version of the typology of the different DRIVER experiments is presented below. The original and preliminary typology based on the understanding of anticipated activities as per October 2014 still serves as a basis, but some clarification is necessary.

### 3.1 Typology of DRIVER experiments

The characterization of the different kinds of experiments taking place within DRIVER is relevant in an ethical perspective mainly as PRIO, through WP95, indicates anticipated tasks that will most likely need approval. It is still the impression of PRIO, that the majority of the DRIVER experiments will happen on the basis of *tactical command & control coordination*.

The term "scenarios" as with "experiments" is understood in broad terms within the project, and implies a wide range of research activities and methodologies. For example, the document "DRIVER Experimentation timeline" from February 2015, lists the various DRIVER experimentation activities in the following way:

- Training, Focus groups
- Table top exercises
- Validation exercises
- System-of-system (SoS) tests
- Functional tests
- Workshops

As described above, from an ethical point of view, the term "experiment" has in itself been topic for discussion (e.g. at the first meeting of the DRIVER ESAB), as there are various existing (and even conflicting) understandings of the term, most likely explained by various backgrounds and experience between the partners in the large DRIVER consortium. As it is impossible for SP9 to assess every individual experiment within DRIVER, the typology is mostly useful for SP9 internal purposes, as it is very important that SP9 closely follow the experimentation activities happening during the project, both to enable revision and refinement of e.g. the societal impact criteria that will feed in to the

DRIVER PoS (WP92 & WP93), but also to understand if additional approvals (also besides data protection) will potentially be needed (WP95), and to tailor eventual guidance in this regard. From this perspective, the typology takes as a starting point the role of human subjects in the experimentation activity, in addition to the nature of the activity itself, and uses this as an indicator to evaluate the ethical implications of the specific activity.

A preliminary typology of the three different types of experiments planned within DRIVER was presented in D91.3. Excluding experimentation through workshops and interviews, those were 1) experimenting through table-top experiments, 2) experimenting through the testing of CM tools, and 3) experimenting through playing out a situation. The difference between experimenting through table-top experiments (e.g. in T52.3) and experimenting through the testing of CM tools (e.g. in 32.4) has been subject to some confusion, (this issue was e.g. raised at the General Assembly in Ispra during the ethics presentation by PRIO). As SP9 understands it at this point, a table top/ desk experiment will typically consist of simulating reality or a real event by formulating a number of preconditions e.g. what tools are available, which personnel participate etc.<sup>17</sup>. It is understood as a desk- exercise with the purpose of training leaders and other key personnel in how to handling a crisis. Testing of CM tools and solutions however, refers to a more hands- on approach to experimenting, where various tools and solutions may be combined and are tested in their relevant contexts and environments. This usually happens in a closed environment, but is not restricted to a lab- or office- setting. The final kind of experiment as identified in D91.3, foresaw experimentation through playing out a situation, where participants were playing out a real-life scenario, which includes unpredictable variables and potentially larger risk of different kinds of harm. While it is not confirmed that such an experiment will be conducted within DRIVER, it is important to pay attention to this, to ensure that potential harms and risks are being handled and minimized in a responsible and sensitive way (as already indicated in Chapter 3.2 of D91.3). Such attention is specially needed if the experiments require withholding information from the research participants.

A “scenario” was in D91.3 understood as part of the methodology for designing what is now suggested renamed to “field experiments” (experiment type 3), but it is clear that the term is used much broader in other SP’s, and that it practically refers to all activities where more or less realistic preconditions are set for the activity. This could also be the case in table- top or desk exercises, as it doesn’t have to be practical, but could also be theoretical or hypothetical.

Based on the overall development in the project, increased operationalization and feedback from consortium members, the typology can be adjusted slightly at this point.

Still keeping “experimentation through workshops and seminars” on the side of the typology, a revised overview of the DRIVER experiments, from an ethical perspective, is suggested as follows: 1) experimenting through desk- exercise (e.g. table-top testing in closed professional environment) of tools (with DRIVER internal participants & professionals), 2) experimenting through testing of tools or solutions (with DRIVER internal participants *and* externals such as volunteers) and 3) field experimentation (public dimension, may be both DRIVER internal and including externals, hence informed consent may be difficult). This typology is most likely to be revised, potentially throughout the project, and must only be seen as a starting point for preparing for the following work in SP9. The typology indicates however, that the most crucial issue in the DRIVER experiments, from an ethical

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<sup>17</sup> Løvik, Kjell (2010). *Øvelse gjør mester*. Kristiansand. Høyskoleforlaget.



perspective, is the nature of the research activity, and how, and to which degree, human subjects are involved.

WP36 is particularly interesting in this regard. For example, in T36.3, experimentation with a mobile application for crowd tasking of individuals (different target groups for preparation: senior citizens, student club, civil society associations), is foreseen. This might be an example of the kind of “field experiment” that will potentially require some additional attention, e.g. if vulnerable groups are included, and there are challenges with regards to informed consent. Also, in T36.2, concepts for pre-disaster organization and concepts for ad-hoc integration of individual spontaneous volunteers are being tested, with students as potentially simulating individuals for the experiments. In T36.1, concepts for integration of non-CM volunteer communities into the response are being tested. Here, a workshop is planned at a DRIVER platform, with students as participants. In sum, although no critical issues are foreseen within these kinds of experiments, the main questions the researchers should ask themselves are exactly what kind of research activity/ experiment is taking place, how the human participants are involved in the experimentation, what kind of risks they face, what kind of data is being collected from them and if the experiments take place in public. These questions may identify critical ethical issues, for example, if the crowd tasking- exercise in 36.3 is foreseen taking place in public, or if health/ medical data is collected from the volunteers, this requires some extra precautions.

Following the recommendations pertaining to all the different kinds of experimentation in D91.3, the key issues outlined there are still relevant. However, it can be underlined that as it looks like there might be experiments happening which have traits of a “field experiment” with human participants, potentially taking place in public (where not all bystanders can be informed about the activity in advance), some additional points should be made. First, as much information as possible should be given to the participants and the bystanders. Evaluations of a large catastrophe exercise in Oslo in 2007 for example, concluded that the need for information (both between crisis managers and between the public and the crisis managers/ government) during a crisis is underestimated in an almost systemic way<sup>18</sup>. This lesson also relates to the flow of information during an exercise.

Another example is that one of the lessons communicated from the large Scandinavian crisis exercise SkagEx11 was that the safety- and risk mitigations for the exercise functioned well, as no participants were [physically] hurt<sup>19</sup>. For DRIVER, it should be underlined that for a set-up for a CM exercise to function well, the success must include both prevention of physical and mental harm. Further, if a field experiment in public with volunteers (e.g. vulnerable groups) is taking place, information regarding de-briefing and follow-up for the volunteers are strongly encouraged. **In sum; approvals required for all research activities/ experiments with human participants are informed consent and data protection approval. Most relevant approvals required from some experiments might be documentation of additional risk mitigation in situations of physical or psychological danger (in which case- contact PRIO), or documentation of elaborate informed consent and safe storage (in case of sensitive data collection etc.).**

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<sup>18</sup><http://www.kommunikasjon.no/fagstoff/krisekommunikasjon/vi-undervurderer-andres-behov-for-informasjon-i-kriser>

<sup>19</sup><http://www.dsb.no/Global/Nasjonal%20beredskap/Dokumenter/Beredskapskonferansen%202012/SkagEx11.pdf>

### 3.1.1 Affecting the public?

The questionnaire devised to solicit feedback from the DRIVER partners for this deliverable asked the question about whether the DRIVER experiments will affect the public in any way. This was intended to indicate potential ethical issues that may arise in relation to this kind of experimentation, and to raise awareness with regards to the conditions that may trigger other kinds of ethical approvals (beyond data protection). While the large majority of the respondents answered no to this question, one particular issue could be mentioned here. For the large-scale experiments/ field experiments (such as a crowd tasking exercise) there might be bystanders, and even bystanders who might decide to join the experiment. In the latter case, the bystanders will reportedly be notified by the simulation organizers and provided with information of what is happening. While the details in such a particular case will be worked out bilaterally between the relevant partner(s) and relevant authority/ PRIO, a preliminary issue that have already been raised is the challenge of obtaining an adequately detailed informed consent, while keeping the text very short.

### 3.1.2 Inflicting harm?

The questionnaire also asked the question of whether the participants in the DRIVER experiments were at risk for potential physical or mental harm of any kind. This is an important principle that could trigger the need for other kinds of ethical approvals. While the great majority of the respondents clearly said no to this question (could also be explained both by varying definitions of “harm”), a couple of unclear cases should be mentioned here. One group of cases has to do with the fact that the activity has not started yet, and that as long as the methodology of the exercise is undecided, this cannot be clearly stated. Other issues have to do with the fact that realistic crisis simulation has to include a bit of stress in order to be realistic, and that some degree of stress is necessary for e.g. training in realistic conditions. Here, the indication is that it is the proportionality of the stress that is the deciding factor. This refers to what have previously been described in this deliverable as a normal and integral part of simulation through the use of scenarios in crisis exercises. Another issue when including vulnerable groups such as asylum seekers, is the fact that as they have most likely left their countries of origin due to trauma, talk of crisis could be triggering for such trauma. In this case, the general rule is that as long as active and thorough informed consent in the appropriate language is in place, this should not be problematic. If minors are included in vulnerable groups taking part in the experiments however, this should be discussed in particular with PRIO or the relevant (local) Data Protection Authority or Ethics Committee. Similarly, engaging participants in the DRIVER experiments in practical activities, such as filling sand bags and physically interacting with other participants in team building exercises and similar, is not a problematic issue if the normal regulations for data protection and informed consent are followed.

## 3.1 Human subjects

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The role of human subjects in DRIVER basically refers to all forms of research, experimentation, testing and demonstration where humans are involved. Further, this means that wherever human beings are involved in research activities, measures are to be taken to ensure their safety and wellbeing.

Although it might initially seem as a philosophical and vague consideration, it is relevant for crisis managers to consider that humans are both a biological, emotional and spiritual being. Both during crisis exercises and real events this consideration will come into play. A practical example of religious impact for example, could be the belief that destiny controls our fate, something which is very different than the logic of crisis managers and personnel.

The reason for the distinction between CM experts/ professionals and the public for example has to do with what is described in D32.1 “Report on risk perception” as differences in their perception of risk. This includes both distinctions between probability, the potential for rational choices, and amount of experienced degree of control in the situation. Although “expert risk perception” cannot be generalized, the socialization of values and risk perception will be more similar within the group of experts than outside. This is also relevant during the exercise in itself, as having external participants with operational knowledge about crisis exercises or experiments, but don’t know the specifications of this one, could bring in a different vision and ask all the “obvious” and naïve questions.

### 3.1.1 The basic psychology of crisis exercises

It is very likely that the crisis manager does not know much about the volunteers and participants in an exercise/ experiment. Their personal experiences and personality traits are rarely known. One example of an exercise where this had unwanted effect was during a so-called field experiment where a hostage situation was being played out in a high school. The older students had been allowed to watch as the exercise took place, and while it was not particularly violent, shouting and threatening behavior took place during which one girl in the crowd started crying and became very upset. It turned out that she was deaf, and none of the crisis managers in the exercise had explained to her what was happening<sup>20</sup>. Within SP3 and the work focused around societal resilience, the reaction of humans after being informed in crisis situation is for example studied in WP35, while the psychosocial support of humans is a core topic in WP32. In WP36, tracking of volunteers in crisis management is studied, as it may be helpful to provide them with appropriate task and to better understand the information they provide. All exercises which tests human reactions should be well thought- through and follow ethical guidelines. In exercises where the scenario is graphic, disturbing or have the potential of evoking strong negative emotions (could also be the case for testing how someone react with the use of a certain technology during a crisis), a person dedicated to following up eventual reactions and follow up with the relevant people should be present, and should be made known to participants.

### 3.1.2 Vulnerable groups

It is of fundamental importance to protect the interests of the research subjects participating in the research activity. The harms that can arise may be of the more self-explanatory kind, such as stress, psychological harm or loss of self-esteem, but even the very fact of being labelled as a group of “vulnerable” might invoke negative reactions with the individuals. This is particularly a risk if the individual is not recruited from a group or association where the “vulnerability” is the common trait of the members. For example, if participants for a study on physically disabled individuals are being recruited from an interest group for physically disabled individuals it is less likely to cause negative effects with the individuals than if the recruitment happened more randomly or even on the street.

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<sup>20</sup> Løvik 2010 : p. 60

Recruiting from an organization may here be an example of best-practice. In DRIVER, some target groups for interviews and focus groups may have a special vulnerability. So far in DRIVER, two main groups of vulnerable groups have been identified: migrants and disabled people (sensory & physical). According to the DoW, experiments shall rely on adult healthy volunteers, since crisis management is to a large extent carried out by such persons.

### 3.2 Informed consent in DRIVER

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Problems can occur if the methodological requirements for research activities that include human individuals come into conflict with the requirement of informed consent<sup>21</sup>. “Work and play” is the definition of an experiment where only the wider timeframe is known to the participants, for example that the experiment will take place within the next three weeks, the next week, or during a certain day, but no more specific information. The purpose behind such a strategy is that the participants should not know exactly when the experiment takes place, and that the experiment should happen within the normal workflow or everyday business of the participants. For this kind of experiment or similar experiments with more unclear organizational structures, informed consent can be challenging, because withholding information may be a necessary requirement.

**To get informed consent means that participants must consent to participation in full knowledge of: What the premises and methods of the procedure are, the aims of the research, the risks involved in participation, who will carry out the procedure, who will benefit from the procedure, how personal data will be collected, used, stored, and destroyed, and that withdrawal is possible at any time.**

The large majority of the partners that have given input to this deliverable reported that they had used or are planning to use the informed consent template provided by PRIO in D91.3.

Four partners reported that some problematic issues relating to informed consent had appeared.

- One issue had to do with “language acquisition”<sup>22</sup> and recruitment of participants through so-called “gate-keepers”.
- Another partner also stated the need for the informed consent form to be in the native language of the participants, and also that informed consent might be considered inappropriate by emergency responders as this is not used when they are participating in professional table-top exercises organized by their own organization<sup>23</sup>.
- The length of the informed consent form that is needed for the use of a mobile application is an issue. If it is too long, no one will read it, if it’s too short, it might miss information<sup>24</sup>.
- Another issue had to do with border- crossing informed consent (reportedly now resolved).

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<sup>21</sup> <http://the-sra.org.uk/wp-content/uploads/ethics03.pdf> p.32

<sup>22</sup> Understood as the need to provide informed consent forms in the native language of the participants.

<sup>23</sup> As noted by one of the reviewers, the issue of which kinds of research activity raise ethical issues and therefor need approval is different from the issue of which kinds of activity qualify as ‘research’ in the context of ‘research ethics’. This distinction is suggested to be consulted with a university research ethics board.

<sup>24</sup> The participants in a crowd tasking experiment will only be able to get generic information about the exercise, and only those who choose to participate in the experiment by downloading and using a mobile application will receive more information. The challenge here is described as keeping the length of an informed consent form on a mobile short enough so that the participants will read it and long enough so that the most important information can fit.

Other partners reported that issues might occur at a later point in time, relating to the use of informed consent. Generally, the best way of preventing such problems is to ensure that common data protection procedures are put in place, but some other problematic issues foreseen by some partners at this point is e.g. that participants may be annoyed that they have to sign a paper for something that they wish to take part in, understood in the way that such a demand might be seen as an unnecessary hinder. Another issue is again the one of language, and that some partners might need to translate informed consent forms (and potentially other kinds of information/documentation) into the native language of the participants. This is a financial as well as a practical and organizational issue. A final issue mentioned in the questionnaire is that as the participants have to ask their organizations for permission to participate in interviews, this could mean administrative delay.

The large majority of partners giving input to this deliverable, report that they are able to obtain full, active and informed consent from the participants in their respective activities. However, some moderations are given, and these mainly relate to the use of scenarios as a methodology of experimentation. Simulating through the use of scenarios is a significant part of the DRIVER experiments, and to not be able to give full insight in what the scenarios will consist of to the participants/ researchers/ technologists beforehand, is generally not a problem (based on the knowledge about the DRIVER experiments at this point in time). In fact, to only provide the necessary amount of information to a participant in the simulation is the only effective way to perform this kind of exercise, as an element of surprise is crucial to keep it realistic (for example when testing how participants deal with new CM solutions, you cannot tell them about all their options). The key word is *proportionality*, and the problematic issue only appears if participants are in fact being put at risk of physical or mental harm during the experiments, and that there is a real risk of the participants having chosen to back out of the activity had the nature and content of the experimentation (scenarios) been known to them in advance. **The main rule is that as much information as it is possible to give without compromising the foundation of aim of the methodology should be given to the participants beforehand.** In one exercise for example, different groups of participants will be given different amounts of information. They will be informed that some light physical activities are to be performed by them, but not exactly what kind of activity. If the method of research is based on observation or simply seeing how an individual or a group of individuals reacts to something, it is likely to be impossible to obtain full informed consent beforehand. It might even defeat the purpose of the research activity. For partners testing the responsiveness of volunteers or volunteer management solutions in general, in some cases, the researcher may even feel it is appropriate to encourage a sense of duty to participate in the activity in order to minimise so-called “volunteer bias”<sup>25</sup> (which can also be influenced by a participant’s professional superiors, friends or colleagues). If it is impossible or counterproductive to get informed consent about the full length of the observation or parts of it, one option is to make an effort to obtain this consent post hoc, in terms of processing of the personal data etc.

### 3.2.1 Informed consent for vulnerable groups

A major limitation upon gaining informed consent lies with “vulnerable” populations. Such groups include minors, disabled, elderly or people who are in a dependent relationship to the researcher or

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<sup>25</sup> <http://the-sra.org.uk/wp-content/uploads/ethics03.pdf> p. 29

commissioning body. For example if an employer asks its employees to participate in a study, it might be difficult for them to resist due to the fear of it having implications. If conducting research with vulnerable groups, particular care must be taken to protect their rights and ensure that their participation is voluntary and informed. Informed consent may serve as an indication that the (vulnerable) subjects understand some of the implications of their consent to participate, but it may also compromise principles of confidentiality and anonymity – an equally valuable principle. Some therefor suggest that signed consent forms “might only be appropriate for longitudinal and/or more intrusive studies” (SRA 2003: 30). For DRIVER however, the rule of thumb is still that informed consent should be sought from all individuals participating in the research activity, and further that the researcher should be explicit about their rationale for gaining consent and upon how “informed” their subjects can be considered to be. It is impossible to safeguard definitely against all possible harms and risks. But there should, as a minimum requirement, be clarity about opt-in and opt-out arrangements, about the length and degree of commitment required of respondents, and about the precise goals of the research. Adequate subject de-briefing also seems essential to this last aim<sup>26</sup>.

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<sup>26</sup> The content of this sub-chapter is largely based on chapter 4.2. « Obtaining informed consent » in the SRA’s «Ethical Guidelines» (2003). Available at: <http://the-sra.org.uk/wp-content/uploads/ethics03.pdf>

## 4 SP9 and DRIVER ethics

### 4.1 What can SP9 do for you?

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This part of the deliverable addresses the work done by SP9 in DRIVER so far, and also the interaction between SP9 and other sub projects and project partners. One of the questions asked in the questionnaire was how SP9 can work better for you, referring to specific work and tasks in the project. Some of the key issues and trends derived from the answers are reflected below, but very particular and detailed issues for a specific partner will eventually be addressed in bilateral communications with the relevant partner, and potentially reflected in the forthcoming organization of work in SP9.

Although what has been described as the “helpdesk-function” of SP9 is considered a desirable asset for some partners, other partners express the wish that SP9 should have less of this function. Here, it should be noted that to a large extent, SP9 can indeed be approached with particular ethical issues arising during the project, for example specifically challenging experimentation activities. However, as stated on several occasions (latest in the email sent by the Project Coordinator to the DRIVER Consortium 28<sup>th</sup> April 2015) sending the applications/ notifications in time, and obtaining the approvals are finally the responsibility of the task leader.

The wish for check-lists or decision trees for experimentation hosts and others, for example for deciding if experimentation requires approval<sup>27</sup> (including guidance on ethics in the experiment evaluation sheets), for data storage and collection and similar is requested by several partners, and this also relates to the wish that SP9 should provide less theoretical information and less concepts, and more recommendations in “action form”. It is suggested that SP9 provides a one-page about experimentation in crisis management (that could for example be sent to relevant authorities on demand), and also to write a one- page (potentially a checklist) on “normal” exercises in crisis management (such as flooding and forest fires) where partners can check if they are within the scope of “normal” exercises and hence do not need to seek further approvals.

Regarding the management of relevant approvals, the wish for a contact point in each of the DRIVER partner states to deal with local authorities has been expressed, and also that SP9 could review the design of the experiments before applications is submitted to the relevant data protection authorities, for example by appointing a SP9- representative in the Expe41 experiment committee. The wish for a table where the different relevant authorities in the different DRIVER partner states are listed has also been expressed (a link to contact information to all European DPA’s is provided in Chapter 2.1 of this report).

The task of SP9 is to collect the ethical approvals and to give guidance (mainly through deliverables) for how project tasks can be carried out in the most ethical way in all the 13 DRIVER partner states. The general assumption is that the partners know the respective administrative and legal regulations in their own country best, and that it would require a tremendous effort from SP9 to investigate such regulations and practices in all the 13 DRIVER partner states. The individual task leader has final responsibility for the ethical issues that might arise in relation to the task. However, general

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<sup>27</sup> Table provided in Chapter 2.2.1.

guidelines and procedures have already been provided, and as these are largely grounded in the EU directive on personal data, the information is possible to give in a rather general and overall applicable way. For more challenging cases, more specified national regulations may need to be investigated. An updated version of the preliminary table where tasks where approval are most likely needed (covering M6-M18), is included in the last sub chapter. It is important to underline however, that although this indication is made by PRIO, it is the responsibility of each partner to check whether their tasks require approval, and to obtain this approval. It is also important that information about postponed activities, or new activities not indicated in the DoW, is reported to PRIO.

## 4.2 How has SP9 influenced your work so far?

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The question about how SP9 has influenced the work in DRIVER so far was intended to solicit both positive and negative constructive feedback on what works, and what can be improved in the way SP9 has organized and carried out the task of monitoring the ethical aspects of the project so far. The feedback can be roughly divided in four categories.

### 4.2.1 Practical guidance

First and foremost, the partners reply that SP9 has provided valuable practical guidance and help in planning for approvals. Many also report that the outputs and guidelines provided by SP9 has been followed and read closely and that SP9 has been an integral part of the preparatory phase, and helped formulate and made suggestions for informed consent forms, an effort being described as good and valuable. Replies also confirm that SP9 has guided partners in the process on how to obtain approvals from relevant Data Protection Authorities. This includes providing a template for Informed Consent (see annex) which the large majority of respondents reported to have used or are planning to use, and a template for Data Protection Approval (see annex) which approximately half of the respondents reported to having used in their work already.

In sum, SP9 has provided support in SC15- related issues, which in itself has proven to be a work-intensive effort with some country/institution specific processes that has been particularly challenging. This has also resulted in some time-intensive discussions with partners and administrations to fulfil the needs and requirements, which is understood by some partners as a more disadvantageous side effect of SP9. Furthermore, one partner worry that the formalization of ethical aspects may even discourage volunteers to get involved in the research activities within the project, as the reflections necessary in this regard is happening more on a meta-level. It must again be noted however, that the requirements, regulations and legislations are not an invention of SP9, but reflect fundamental principles and rules for high quality European research.

### 4.2.2 Awareness raising

The first step of giving practical guidance in relation to ethical research is to raise awareness of which activities and experiments might trigger the need for particular attention and approvals. This work started in SP9 early on in the project, and the basic principles for ethical research was presented in D91.3, submitted already in M6. According to the feedback from the questionnaires, SP9 has contributed to raise awareness in particular on the following issues: 1) ethical issues and requirements for design and planning experiments, 2) ethical issues in general, 3) particular



requirements for data protection and informed consent, 4) how to do not just the minimum regarding ethical issues (best practice), and 5) on possible positive and negative impacts that research on crisis management can play on society and its influence on increasing societal resilience.

#### 4.2.3 Encouragement

According to the feedback, SP9 has also encouraged partners to investigate ethical issues more thoroughly, and has reinforced the need to consider ethical issues whenever dealing with human participants. As previously described, for some partners the consideration of ethical aspects is a rather new variable of their work, making the adherence or fulfilment of ethically related obligations a more or less obvious task. In this regards, the questionnaire shows that SP9 has also provided some partners with new insight into how to connect societal issues to operational crisis management, and that this issue has been part of a discussions resulting in interesting reflections within some SP's. The issue of implementing considerations of societal issues into operational crisis management is one of the overarching goals of SP9, and obviously this work is merely in its beginning.

#### 4.2.4 No direct impact at this point

The final, and largest, group of respondents reported that SP9 has not yet played a significant role or been of particular influence for their respective work in DRIVER. This can at least partially be explained by the fact that many of the DRIVER experiments and activities that include individuals participating (particularly when they are external to DRIVER) has not yet started, and therefore no ethical issues have appeared at this point. For these partners, the questionnaire distributed for this deliverable will hopefully raise awareness and potentially serve as a reminder or indication of what kind of issues might require particular attention once the activity starts. Although for several partners not a lot of input could be provided at this point, the general attitude towards interacting with SP9 in the future as reflected in the questionnaires can be described as positive.

### 4.3 Other ethical issues?

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The last part of the questionnaire allowed the partners to raise any other (potential) ethical issues that they assumed could be of importance. The large majority of the partners who filled out the questionnaire did not wish to raise any other ethical issues at this point in time. Again, this can be explained by the fact that a lot of activities have not started yet, and that it is not yet clear if ethical issues might arise. It may also indicate that the presumably most relevant ethical issues are already being tackled in SP9. However, a couple of issues were raised, but these were basically reflections of other issues that had already been raised in other section of the questionnaire. A rather concrete description of support needs with regards to specific WP's was expressed by SP3, and these are listed below (also as they exemplify the expectations to SP9).

- Dialogue on potentially negative societal impact (WP32), advice on how to formulate specific messages for specific groups (WP33), overlaps and correlations between governance activities and societal aspects? Support design phase and experimentation phase (WP34), review ethical consent forms (WP35), focal point for all experiments (SP3 all WP's), help to formulate ethically compliant guidelines for crowd tasking operators (WP36- E36.2), collect

one ethical approval for a group of experiments following the same concept (crowd tasking in WP36, WP43, WP44).

#### 4.4 M12 status update on expected approvals needed for the second round of approvals (M6-M18)

Below is a table indicating the tasks identified by PRIO in M6 as being expected to require approval by the next round of Ethical Approvals, which will be submitted through D95.23 “Ethical Approval 2”, in M18. The table covers tasks between M6 and M18, and the table below shows the status regarding approval for the different tasks, as they stand in M12, 30<sup>th</sup> April 2015 (date for submission of this deliverable).

Task	Task partner	Start Activity	Status
T32.2	DRC *	M4	DRC (Cecilie Dinesen) confirmed that WP32 does not need approval. Documentation from Ethics Board and DPA received.
T32.3	DRC *	M4	See above
T36.2	USTUTT	M10	Added to the list by Christian Kloyber (ARC) on 01.10.2014
T36.2	AIT	M12	Added to the list by Christian Kloyber (ARC) on 01.10.2014
T24.3	FOI	M11	
T46.1	TCS	M11	
T52.2	FHG-IAO	M11	Received 22.10 (sent by Bernd Dworschak to Anne and Mareile)
T61.1	DLR	M11	
T64.1	ATOS	M11	Application to DPA forwarded to PRIO by Fernando 17.03.2015
T53.1	FOI	M12	
T34.2	USTUTT	M13	
T35.4	Q4PR	M13	
T36.3	FRQ	M13	Task is combined with 36.4
T27.2	JRC	M15	
T46.2	ATOS	M15	Not included in the application

			forwarded to PRIO by Fernando 17.03.2015. Will personal data be collected after all?
T66.1	POLE	M18	

**Table 1 Calendar of approvals M6-M18**

\*According to the task leader the approvals was needed by month 7 only

= No application/ approval received by PRIO

## 5 Ethical and Societal Advisory Board (ESAB)

The Ethical and Societal Advisory Board (ESAB) is an independent committee that advises DRIVER, and specifically SP9, about ethical challenges and societal aspects of crisis management and research done throughout the project. The first meeting of the Ethical and Societal Advisory Board was held on 4<sup>th</sup> of December 2014 in Brussels. The minutes from the meeting were translated into Deliverable D95.11<sup>28</sup>, which was submitted 31.12.2014. The Ethical and Societal Advisory Board will continue to meet annually, each meeting taking as its point of departure the review report.

### 5.1 Summary of the first ESAB meeting

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The members of the ESAB are: Helene Ingierd from NENT - The Norwegian National Committee for Research Ethics in Science and Technology, Vasiliki Petousi from the University of Crete, and Katerina Hadjimatheou from Warwick University/ the ADVISE project. Also present in the first meeting was Peter Burgess, Mareile Kaufmann & Stine Bergersen from PRIO (SP9 leader), Merle Missoweit from Fraunhofer-INT (CT), Fernando Kraus from ATOS (Project Coordinator), Myriam Ben Ammar from ARTTIC (SP7 leader) and Guillaume Lapeyre (Project Officer, European Commission). The first ESAB meeting was mainly used to introduce the members of the ESAB to the project, and to discuss some issues that had arisen already. The meeting was dedicated to clarify the overarching goal of the DRIVER project and the role of SP9 in particular and furthermore to solicit feedback about the further integration of societal impact criteria throughout the project and about some specific scenarios vis-à-vis the ethical approvals.

One of the key issues which were raised at the meeting, from the side of the Ethical and Societal Advisory Board, were the confusion with regards to the use of the term “experimentation”, which the board had the impression that DRIVER does not engage with as they know the term. All DRIVER tools and measures will be tested in experiments, and the ESAB asked about the meaning of the word “experiments” and what level human participants will take part in these. At this early stage of the project, it was foreseen that experiments would include human participants only as assessors or supervisors of the testing of tools. Human participants are more likely to be part of follow-up surveys and interviews. However, after the DRIVER meeting week in Ispra in February 2015, it is also clear to SP9 that some of the experiments (especially within SP3, and potentially in SP6) will include civilians and spontaneously recruited volunteers, engaging in research activity that is foreseen to go beyond desk research, workshop activities, testing in a lab etc. Although it is not anticipated that the ethical considerations will hinder the desired experimentation activity, it is important that the board continues to get updates on the nature of the research activities and the role of human participants in the experiments, also in order to be alert and seek advice on whether there are particular combinations of activities or conditions that might trigger additional ethical issues that could potentially be problematic.

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<sup>28</sup> See D95.11 for the full ESAB meeting minutes. This deliverable also includes a PowerPoint presentation including all of the project presentations, as well as key discussion points and action points.

Another potential issue raised by the board to keep in mind, is that if parts of the projects outputs are driven by commercial goals, this might be an issue and create conflicts of interests at a later point in the project. Also, the board agreed that the methodology needed by SP9 for assessing the DRIVER tools or functions, which will feed into the PoS/ testbed(s) is important to clarify, and that this question will be investigated throughout the project, and can also be further explored in the coming sessions of the ESAB. Finally, four specific scenarios of data collection and data sharing (derived from the actual experience of PRIO through WP95) were presented to the ESAB, and their advice was requested. These scenarios were discussed, and feedback was given from the ESAB and the other participants. Some issues were also followed up by email after the meeting. For a closer description of the scenarios and the suggested solutions by the ESAB and the other participants to the meeting, please see D95.11.

## 5.2 Issues suggested by partners to be raised to the DRIVER ESAB

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The questionnaire asked the partners the question of whether there is any issue that they would like SP9 to bring forth to the ESAB. Although the great majority of partners did not have any suggestions, a couple of issues and insights have already been identified by the consortium partners, which will be raised to the DRIVER Ethical and Societal Advisory Board (ESAB) in later meetings, if needed.

### 5.2.1 Sensitive data

The first issue has to do with the distinction between *sensitive personal data* and *personal data*, and some general information can already be given here. Sensitive personal data is data consisting of the following information: race or ethnic origin; political opinions; religious or other beliefs; trade union membership; health; sexuality; or alleged or actual criminality.<sup>29</sup> The collection and processing of personal data, as described in Chapter 2.2, entails a number of precautions. The issue of sensitive data also entails such precautions, for example with the practical implication that the informed consent form must specify that it is indeed sensitive data that is being collected. In addition to the regular procedure, dependent on the national legislation and guidelines from the national DPA, it is very likely that other rules apply. In some countries (such as Norway for example), the DPA states that sensitive personal data must be stored or held separately to normal personal data, and that to ensure the security of the sensitive personal data, the storage often takes place in separate “zones” (physical or digital) with restricted access (such as password etc.).

### 5.2.2 Data storage

The potential solutions for storage of personal data is another issue identified, and the very general rule is that the data collected and processed in DRIVER must be stored in a secure and safe manner (see also Chapter 6.1). The concept of privacy-by-design (or built-in privacy) basically refers to the inclusion and consideration of privacy in all development phases of the solution or system. Privacy-by-design is not required by law, and it is up to each partner/ company/ system developer etc. to decide if privacy-by-design is implemented, for example if it is explicitly desired from the ethical authority. Regarding the location of the stored data, there is also a distinction between “putting the data on a central server” and “keeping the data on the user’s device”, which might require further

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<sup>29</sup> University of Oxford (2012) “Data Protection and Research” Legal Services Briefing Note, p.4

investigation by SP9 in the later phases of DRIVER. In the former case, this might on the one hand include a higher risk of function creep/ dual use, as the data is kept in one place, but on the other hand it might be easier to apply and ensure coherent data protection measures (as it is clear who the data controller is). In the latter case, the user has more control of the data, but if the data is *personal* data, there are several administrative requirements that are easier to fulfil if the data storage is centralized.

### 5.2.3 Formalization of ethics

The final issue is interpreted by PRIO as an unfavorable formalization of ethics. Adherence to the research ethics described in this and previous deliverables from SP9 are to a large extent unavoidable, and a fundamental condition for scientific soundness and good practice in research (and again: are *not* a product or invention of SP9). In fact, the high level of attention devoted to ethical (and societal) considerations and impacts within the project could indeed be seen as an added value of DRIVER. This issue relates perhaps in particular to the inclusion of external (to DRIVER) individuals in the project's activities, where volunteers are likely to be more aspiring to partake in the subject of the matter, and not to engage with the more formalized rules of research ethics. However, it is foreseen that the guidance from SP9 will become more practical and operational as the project activities/ experiments become more practical and operational.

## 6 Mitigation of risks for crisis management solutions and tools

### 6.1 Mitigation through Data Protection

Security architecture is a broad field, where the key starting point is the principle of distinct and logically separated networks<sup>30</sup>. It is very likely that the national Data Protection Authority will have information sheets or provide other kinds of guidance when it comes to the specific instructions and recommendations for ensuring sound security architecture to sufficiently protect personal data.

The first step in creating privacy- friendly solutions for crisis management is to evaluate the consequences the solution or tool will have for the privacy of the data subjects targeted by the tool, or the users of the tool. An evaluation (such as a Privacy Impact Assessment) can for example include the following: i) ensuring that the processing and collection of personal data is in line with the relevant data protection regulations, ii) considering the risks of processing the data electronically, iii) considering if there are other methods for reaching the goal set out by the tool which limits or minimizes the need for collection of personal data, and iiiii) investigating if the personal data is actually protected in the best possible way in the relevant system, or if there are better ways of taking care of this<sup>31</sup>.

Through such an evaluation, risks connected to the protection of personal data can be detected, and thus made possible to avoid or reduce. This kind of evaluation (which can be done with varying depth) is important because it gives the owner or user of the tool several advantages. First and foremost, privacy- friendly tools or solutions take better care of the privacy of their data subjects. Also, it may invoke trust with the users to be aware that such evaluations and considerations have taken place, and it may be a positive factor in case of an unwanted incident such as a security breach, as it may be documented that the company/ owner/ user has considered the possibility for such incidents to happen and thus are better prepared for it. Finally, it may reduce costs, as it is usually less costly to amend details at the planning- stage than to change a finished product (and often it is not even possible to do so)<sup>32</sup>.

The obvious, easiest and most reasonable way of mitigating the risk of breaching the data subject's privacy is to **make sure that you do not collect any data that you do not need**. This is known as the principle of data- minimization. For example, a tool or solution may need to collect geo-location data, but it may be possible to encrypt the rest of the data, which is not necessary for performing the exact function of the tool. In general, data that is irrelevant to the purpose, superfluous, out of date, or no longer necessary should be deleted, if at all collected. In this way, the risk is mitigated through minimizing the potential range of the negative impact. The measures resulting from an assessment can be twofold. They may be technical (such as making changes in the system architecture,

<sup>30</sup> <http://www.datatilsynet.no/Sikkerhet-internkontroll/Sikkerhetsarkitektur/>

<sup>31</sup> Example taken from : <http://www.datatilsynet.no/Teknologi/Vurdering-av-personvernkonsekvenser---privacy-impact-assesment/Hva-betyr-det-a-vurdere-konsekvenser-for-personvernet/?showContentList=true&showDetailedContentList=false&readMode=false>

<sup>32</sup> *ibid*

encryption, or default settings) or they may be organisational (such as limiting access to the databases for the individuals that need it or the use of confidentiality declarations)<sup>33</sup>.

In addition to the obligation to inform the data subjects that data is being collected from them, the data controller is obligated to provide the data subject access to the collected data if requested. However unlikely and irrelevant this event may seem at the development stage of a tool or solution, it is highly recommended to take this into consideration and prepare for the eventuality. The right to access is further described in the European data protection regulatory framework and in particular the European Data Protection Directive 95/46/EC<sup>34</sup>. The other side of this right is the obligation to inform about the fact that data collection is happening, usually ensured by descriptions in terms & conditions or for more direct data collection, though informed consent sheets. This precaution will mitigate the risk of not being able to fulfil the duty of the data controller in case certain personal data rights are being exercised.

In sum, some recommendations can be given for mitigating risks of negative impacts to privacy<sup>35</sup>:

- The assessment of potential privacy implications should be done as early in the design/planning process as possible.
- Consider who within the organisation is most suited to assess privacy implications.
- Identify which issues should be assessed. This is most likely related to the rules or routines for the collection, processing or sharing of personal data.
- Make sure that the assessment does not compromise the internal interests of the organisation, or that it does not obstruct goals that the organisation has for development or deployment of the relevant tools or solutions.
- Document that a privacy impact assessment has taken place<sup>36</sup>.

The Norwegian Data Protection Authority has discovered, in a large number of cases, systematic violations in the current regulations regarding the obligation to delete data and to not re-use data for novel purposes<sup>37</sup>. This partly has to do with the fact that data storage is becoming increasingly inexpensive, and it is usually more expensive to establish routines for deletion than to just keep storing the data. While the general rule is that data should not be stored beyond its need for a certain purpose, this often happens, e.g. with the argument that the data might be needed at a later point although the purpose is not completely clear at this point in time. The storing of excess data is not only a breach of data protection regulations, but it also increases the risk of function creep and/or dual uses (see D92.11 p. 22 for definition of *function creep*, see D91.3 p.10- 11 for explanation of

<sup>33</sup> <http://www.datatilsynet.no/Teknologi/Vurdering-av-personvernkonsekvenser---privacy-impact-assesment/Hvordan-vurdere-konsekvensene-for-personvernet/?showContentList=true&showDetailedContentList=false&readMode=false>

<sup>34</sup> It is more precisely one of the most substantial of the ARCO data protection rights (access, rectification, cancellation, opposition) because, if you cannot know what data is being held about you, it is not possible to exercise the rest of the rights.

<sup>35</sup> Based on information from the Norwegian Data Protection Authority (Datatilsynet), but generalizable across the EU as the regulatory framework is to a large extent harmonized throughout. See:

<http://www.datatilsynet.no/Teknologi/Vurdering-av-personvernkonsekvenser---privacy-impact-assesment/Hvordan-vurdere-konsekvensene-for-personvernet/?showContentList=true&showDetailedContentList=false&readMode=false>

<sup>36</sup> For an example of a Privacy Impact Assessment (PIA) by the U.S Department of Homeland Security that covers the research phase of the FAST-project (Future Attribute Screening Technology), see :

[http://www.dhs.gov/xlibrary/assets/privacy/privacy\\_pia\\_st\\_fast.pdf](http://www.dhs.gov/xlibrary/assets/privacy/privacy_pia_st_fast.pdf)

<sup>37</sup> [http://www.datatilsynet.no/Global/04\\_veiledere/personvernrapport\\_tilstand\\_trender2013.pdf](http://www.datatilsynet.no/Global/04_veiledere/personvernrapport_tilstand_trender2013.pdf)



*dual use*). In sum, defining a clear purpose for the data collection, and ensuring clear rules for data minimization, deletion, and physical protection of the data will mitigate the potential harmful risks.

## 7 Final Remarks

This deliverable is the first Ethical Monitoring Report, documenting and addressing ethical issues in DRIVER. The next Ethical Monitoring Report is due in M24, and will document and address ethical issues pertaining to the project in the year to come. Being the first Ethical Monitoring Report in the project, in addition to addressing the most relevant ethical issues relating to the current state of DRIVER, this first report has also repeated and refined some core points from previous deliverables; both to clarify some particularly important points regarding research ethics, but also to update and specify some of the previously given recommendations and guidelines. This is based on the knowledge and information accumulation that is already taking place within DRIVER, due to a more operative and practical orientation in the work. For the next Ethical Monitoring Reports, updates on ethical issues will be documented, and relevant issues will be discussed, but it is expected that the following reports will to a lesser degree address fundamental issues relating to research ethics, and revolve more around the practicalities of collecting the approvals, and potential special ethical challenges in the project.

## 8 Bibliography

European Commission. *Frequently asked questions relating to transfers of personal data from the EU/EEA to third countries*. Available at:

[http://ec.europa.eu/justice/policies/privacy/docs/international\\_transfers\\_faq/international\\_transfers\\_faq.pdf](http://ec.europa.eu/justice/policies/privacy/docs/international_transfers_faq/international_transfers_faq.pdf)

European Commission (2015). *Riga declaration on remotely piloted aircraft (drones) "Framing the future of aviation"*. Available at: <http://ec.europa.eu/transport/modes/air/news/doc/2015-03-06-drones/2015-03-06-riga-declaration-drones.pdf>

Honningsvåg, Tor (2011). *Beredskap og krisehåndtering. SkagEx11*. Available at:

<http://www.dsb.no/Global/Nasjonal%20beredskap/Dokumenter/Beredskapskonferansen%202012/SkagEx11.pdf>

Løvik, Kjell (2010). *Øvelse gjør mester*. Kristiansand. Høyskoleforlaget.

Social Research Association (SRA) (2003). *Ethical Guidelines*. Available at: <http://the-sra.org.uk/wp-content/uploads/ethics03.pdf>

The National Committee for Research Ethics in Science and Technology (NENT). *Forskningsetisk sjekkliste*. Available at: <https://www.etikkom.no/forskningsetiske-retningslinjer/Forskningsetisk-sjekkliste/>

The Norwegian Data Protection Authority (Datatilsynet) (2013). *Personvern 2013. Tilstand og trender*. Available at:

[http://www.datatilsynet.no/Global/04\\_veiledere/personvernrapport\\_tilstand\\_trender2013.pdf](http://www.datatilsynet.no/Global/04_veiledere/personvernrapport_tilstand_trender2013.pdf)

The Norwegian Data Protection Authority (Datatilsynet). *Hvordan vurdere personvernkonsekvenser-privacy impact assessment*. Available at: <http://www.datatilsynet.no/Teknologi/Vurdering-av-personvernkonsekvenser---privacy-impact-asesment/Hvordan-vurdere-konsekvensene-for-personvernet/?showContentList=true&showDetailedContentList=false&readMode=false>

The Norwegian Data Protection Authority (Datatilsynet) (2011). *Veileder i sikkerhetsarkitektur*.

Available at: [http://www.datatilsynet.no/Global/04\\_veiledere/sikkerhetsarkitektur\\_veil.pdf](http://www.datatilsynet.no/Global/04_veiledere/sikkerhetsarkitektur_veil.pdf)

Norwegian Social Science Data Services (NSD). *Skal det registreres personopplysninger?* Available at:

<https://trygg.nsd.uib.no/personvern/meldeplikt/meldeplikttest>

U.S Department of Homeland Security (2008). *Privacy Impact Assessment for the Future Attribute Screening Technology (FAST) Project*. Available at:

[http://www.dhs.gov/xlibrary/assets/privacy/privacy\\_pia\\_st\\_fast.pdf](http://www.dhs.gov/xlibrary/assets/privacy/privacy_pia_st_fast.pdf)

University of Essex, UK Data Archive : *Create & Manage Data*. Available at: <http://www.data-archive.ac.uk/create-manage/consent-ethics/anonymisation>

University of Reading, Information Management & Policy Services. *Photographic images*. Available at: <http://www.reading.ac.uk/internal/imps/DataProtection/DataProtectionGuidelines/imps-d-p-photographic.aspx#checklist>

University of Oxford (2012). *Data Protection and Research. Legal Services Briefing Note*. Available at: [http://researchdata.ox.ac.uk/files/2013/12/Data\\_Protection\\_and\\_Research\\_17\\_01\\_2012\\_3.pdf](http://researchdata.ox.ac.uk/files/2013/12/Data_Protection_and_Research_17_01_2012_3.pdf)

Øyen, Jonette (2009). *Vi undervurderer andres behov for informasjon i kriser*.

Kommunikasjonsforeningen. Available at:

<http://www.kommunikasjon.no/fagstoff/krisekommunikasjon/vi-undervurderer-andres-behov-for-informasjon-i-kriser>

## 9 Annexes

### 9.1 Informed Consent Form template



#### General information about the research project (INSERT A TITLE FOR THE RESEARCH YOU WILL CONDUCT FOR DRIVER)

The **DRIVER** project, Driving Innovation in Crisis Management for European Resilience, gathers the expertise of 37 organisations, who will jointly develop solutions for improved crisis management. A distributed pan-European test-bed will be built for experimentation and testing and the most useful new tools will be collected in a comprehensive Crisis Management portfolio at the end of the project. Building upon the findings of previous research projects, DRIVER's ultimate goal is to enhance European resilience in the face of crisis situations and ascertain sustainable innovation in Crisis Management also after the end of the project.

#### Description of Research

The research under the lead of (ADD NAME OF LEAD RESEARCHER & LEAD INSTITUTION) focuses on (NAME MAIN AIM OF THE TASK/S) and is embedded in the DRIVER project.

DESCRIBE IN 5 SENTENCES:

- WHAT YOU DO IN THE PLANNED RESEARCH (IF YOU HAVE, ADD A RESEARCH QUESTION)
- WHY YOU DO IT, WHAT FOR
- HOW YOU DO IT
- HOW THE DATA WILL FEED INTO THE DRIVER PROJECT

#### Selection of participants and treatment of data

DESCRIBE IN HALF A PAGE:

- YOUR SAMPLE (HOW MANY PARTICIPANTS)
- ON WHAT BASIS YOU CHOSE THE PARTICIPANTS, WHY
- HOW YOU CONTACTED THE PARTICIPANTS
- WHAT EXACTLY YOU WANT THE PARTICIPANTS TO DO/ANSWER/TALK ABOUT
- WHAT KIND OF DATA THIS RESEARCH WILL PRODUCE
- WHETHER AND HOW THE DATA WILL BE RECORDED, TRANSCRIBED, ENCRYPTED OR ANONYMIZED
- HOW THE DATA WILL BE STORED, WHERE AND HOW LONG FOR
- HOW THE DATA WILL BE PROCESSED, ANALYZED, WHO WILL HAVE ACCESS TO AND RESPONSIBILITY FOR IT

#### Your participation

Your participation is integral to the project and will contribute to the quality and novelty of research on crisis management and resilience. Participation in the project means that you will

be asked to take part in (DESCRIBE 4-5 SENTENCES WHAT THE DESIGN OF YOUR INTERVIEW/FOCUS GROUP ETC. IS, WHAT GENERAL QUESTIONS WILL BE ASKED OR REQUIREMENTS NEED TO BE FULFILLED). Participation in the interview is entirely voluntary. You will not have to share information that you consider private. Your participation in the project can be withdrawn at any time without further notice. In that case your data will be deleted instantly. We point out that the complete withdrawal of your data may not be possible after the point in time data has been anonymized, clustered or generalized. (INDICATE WHEN IN THE PROCESS THIS MAY HAPPEN).

- WHERE APPLICABLE ADD: Since you will be asked to (EXPLAIN POTENTIALLY UNCOMFORTABLE QUESTIONS ETC.), it is important to ensure that you are comfortable sharing this kind of information.
- ADD A SENTENCE ON WHETHER DATA WILL BE SHARED. IF SO IN WHAT FORM AND WITH WHOM.

The research commenced in May 2014 and comes to an end latest in (ADD END DATE).

- DESCRIBE IN 1 SENTENCE HOW, WHERE, AND BY WHOM THE DATA WILL BE STORED, FOR HOW LONG, HOW IT WILL BE PROCESSED AND WHEN IT WILL BE DESTROYED.
- PROCESSING: DESCRIBE IN 2-3 SENTENCES WHAT INFORMATION YOU WILL DRAW OUT FROM THE DATA AND HOW (GROUPING ANSWERS, MAKING CLUSTERS, MAKE GENERAL RECOMMENDATIONS ETC.)

(LEAD RESEARCHER) will publish the results in such a way that individual views and arguments can never identify participants. The limited personal information gathered will be treated confidentially and (LEAD RESEARCHER) will duly respect this. (DESCRIBE WHO HAS ACCESS TO DATA.)

(LEAD INSTITUTION'S) part of the project is authorized by the (ADD YOUR DATA PROTECTION AUTHORITY, ONCE YOU HAVE APPROVAL).

If you allow (NAME OF LEAD INSTITUTION) to use your data in the project, please express your Consent in written form by signing below.

Your name in block letters:

Participant's Date & Signature:

If you have any questions please don't hesitate to contact (NAME OF LEAD RESEARCHER). Should you have any complaints about the way the research is carried out you can contact (NAME) at (DATA AUTHORITY).

Kind regards,

(NAME, SIGNATURE LEAD RESEARCHER)

(ADD CONTACT DETAILS OF LEAD RESEARCHER)

## 9.2 Template for Research Ethics Approval Application

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### Application for Research Ethics Approval

➔ **NOTE: INSERT A TITLE FOR THE RESEARCH YOU WILL CONDUCT FOR DRIVER**

**Research conducted within the FP7-funded DRIVER project**

**« Driving Innovation in Crisis Management for European Resilience »**

To be Submitted to ➔ **NOTE : FILL OUT RESPONSIBLE INSTITUTION**

➔ **NOTE:** Please fill out the points below. This template is a guideline. Please ensure that you are not obliged to follow particular national guidelines for application provided by your local Data Protection Authority.

All categories and questions below are either directly quoted from or inspired by the **Norwegian Social Science Data Services (NSD) Notification Form**. Available at : <http://www.nsd.uib.no/>

#### General Information

- *Responsible institution*
- *Project leader*
- *Objective of project*
- *Other involved institutions*
- *Who of the involved institutions will have data access?*

#### Sample

- *Sample (number of participants, age, location of participants)*
- *Is the data your own or are you getting it from a different institution (like the Red Cross, the police, administrative files, etc.)*
  - *If yes, please ensure whether or not the institution that provides it to you needs approval from within their institution.*
  - *If no, please proceed below.*
- *How are participants/interviewees recruited? (How will selection take place and how will they be contacted)*
- *Will any legal adult with reduced capacity to legal consent be recruited?*

#### Data Collection

- *How will the data be collected? Please expand on the selected method.*
  - Questionnaire
  - Personal interview
  - Group interview
  - Observation
  - Psychological tests
  - Medical tests

- Records
- Registers

## Data Content

- What is the content of the data?
- Will directly identifying data be collected (social security number, name, date of birth, email, phone number etc.)? Please specify.
- Will indirectly identifying data be collected (it is possible to deduct from background information who the person is likely to be. Background information can be age, gender, part of a specific group etc.). Please specify.
- Will sensitive information about a person be collected? (*“Sensitive personal data includes any personal data consisting of the following information: race or ethnic origin; political opinions; religious or other beliefs; trade union membership; health; sexuality; or alleged or actual criminality.”*<sup>38</sup>)
- Will information about third persons be collected (secondary information from which it is possible to deduct the identity of a third person)? If so, in what way will the third person be informed?

## Informed Consent

- Specify how participants will be informed about the project (verbal, written, will not be informed).
- Specify how participants will give their consent (verbal, written, not at all).

## Information Security

- Is indirectly identifying information replaced by a reference number which refers to a separate list of names?
- How will the list of names be stored, who will have access to it?
- Is directly identifying information registered together with the other data? If yes, please explain why.
- Is indirectly identifying information registered or stored?
- How is the data registered, saved and processed?
- Are audio-, video-recordings and /or photographs saved and/or processed on a computer?
- How is the data safeguarded from unauthorized access?
- Do you use a portable storage device? If so, why and how will it be used?
- Who will have access to the data?
- Will personal data be transferred through the internet? If so, please specify information.
- Will personal data be transferred to anyone outside the project team? If yes, please specify.
- Will data be gathered or processed by an external processor? If so, please specify.

## Approval by Other Regulating Bodies

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<sup>38</sup> University of Oxford (2012) “Data Protection and Research” Legal Services Briefing Note, p.4



- Will your project require a dispensation from the duty of confidentiality in order to gain access to the data? (e.g. data from public institutions) If so, you must apply for a dispensation from the duty of confidentiality at the relevant government departments.

### Duration of the Project

- How long will the project last?
- What will happen to the data when the project is completed?
- Where and for how long will the data be filed?
- Will the data be filed with personal identification? If so, why?
- How will the project be financed?
- Any other relevant information?

## 9.3 Ethical Monitoring Questionnaire

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*Driving* Innovation in Crisis Management for **E**uropean **R**esilience

### - Ethical Monitoring Questionnaire (T95.3)-

In T95.3 PRIO is tasked with preparing regular Ethical Monitoring Reports. These reports will document ethical issues that might arise during research and experimentation activities in DRIVER. Ethical principles are outlined in the DoW Part B4 (p.164) and in particular in D91.3. Please take a couple of minutes to read again Part B4. The purpose of this questionnaire is to gather input from partners to guide the focus and content of the Ethical Monitoring Reports. You are asked to fill in this questionnaire to the best of your knowledge and send it back to [covi@prio.org](mailto:covi@prio.org) and [stiber@prio.org](mailto:stiber@prio.org) by **09 March 2015**. Please contact us for any questions as well.

**As per the DRIVER DoW, the following partners are required to give input: FOI, FHG, POLE, ATOS, ECORYS, MSB, JRC, FHG-IAO, ARC, DRC, ARMINES, CIES, Q4PR, FRQ, AIT, TCS, DLR, GMV, ITTI, EDI, MDA, THG, PSCE, ARTTIC, TNO**

The information collected will be used for SP9 purposes only and will not be shared with outside parties without permission. Personal information will be kept confidential.

#### BASIC INFORMATION

- Name/ email:
- Organization:
- Main SP/ WP's:
- Main role in DRIVER (*end-user, developer, researcher, management, technologist, other*):

#### ETHICAL APPROVALS

1. **Have you or your institution been in contact with local ethics committees or Data Protection Authorities?**

If yes: describe shortly the process, did you encounter any (unforeseen) problems or challenges (e.g. lack of answer, unclear guidelines, or unclear responsibilities)? Did you make use of the data protection approval template provided by SP9 in D91.3?

If no: do you foresee any particular problems or challenges in relation to obtaining appropriate approvals? Please describe.

2. **What kind of experimentation activity are you mainly involved with in DRIVER?**

### **BASIC PRINCIPLES FOR ETHICAL RESEARCH**

3. *(Here, one or more questions aimed at a particular task/ activity/WP relevant to the respondent's organisation was given, where PRIO see potential ethical issues)*
4. **Have any ethical issues come up for your work in DRIVER that you have not experienced before?**

### **HUMAN PARTICIPANTS**

5. **Do you do research on vulnerable groups (e.g. disabled, elderly, minors)?**

If yes: how are you taking special precautions to ensure their well-being and to minimize harm?

6. **Will your research activity/ experiment affect the public in any way? If so, please explain (e.g. are bystanders exposed to the activity/ experiment; are you unable to inform everyone in the close surroundings of what is taking place; etc.)**
7. **Are humans participating in the research activity/ experimentation at risk of being harmed either physically (unsafe working environment, etc.) or psychologically (disproportional stress, discomfort, etc.)? Explain why/ why not.**

### **INFORMED CONSENT**

8. **Did you/ do you plan to make use of the informed consent template provided by SP9 in D91.3?**
9. **Do you foresee, or did you have, any problems relating to informed consent (e.g. participants might feel obliged/pressured to participate in the activity/ experimentation)?**
10. **For testing/ experimenting: are you able to give complete information about the activity to the participants beforehand or does the nature of the activity require you to partly withhold information? If so, please explain.**

## **INTERACTION WITH SP9**

**11. How can SP9 (in particular WP95) make it easier for you to do deal with the ethical issues of your research? (E.g. are you missing a certain kind of information or support? Do you want information/support in a different format?)**

**12. In what way has SP9 influenced your work so far?**

**13. Are there any ethical issues you would like SP9 to bring forth to the DRIVER Societal and Ethical Advisory Board?**

## **OTHER (ETHICAL) ISSUES**

**14. Is there anything else relating to research ethics in your work in DRIVER you would like to share?**

**Thank you for your cooperation!**