driver+

Driving Innovation in Crisis Management for European Resilience

D913.12 – ETHICAL APPROVAL

(ETHICAL ISSUES AND LESSONS LEARNED FOR TRIALS)

SP91 - PROJECT MANAGEMENT

DECEMBER 2018 (M56)

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The DRIVER+ project

Current and future challenges, due to increasingly severe consequences of natural disasters and terrorist threats, require the development and uptake of innovative solutions that are addressing the operational needs of practitioners dealing with Crisis Management. DRIVER+ (Driving Innovation in Crisis Management for European Resilience) is a FP7 Crisis Management demonstration project aiming at improving the way capability development and innovation management is tackled. DRIVER+ has three main objectives:

1. Develop a pan-European Test-bed for Crisis Management capability development:
    a. Develop a common guidance methodology and tool, supporting Trials and the gathering of lessons learnt.
    b. Develop an infrastructure to create relevant environments, for enabling the trialling of new solutions and to explore and share Crisis Management capabilities.
    c. Run Trials in order to assess the value of solutions addressing specific needs using guidance and infrastructure.
    d. Ensure the sustainability of the pan-European Test-bed.
2. Develop a well-balanced comprehensive Portfolio of Crisis Management Solutions:
    a. Facilitate the usage of the Portfolio of Solutions.
    b. Ensure the sustainability of the Portfolio of Solutions.
3. Facilitate a shared understanding of Crisis Management across Europe:
    a. Establish a common background.
    b. Cooperate with external partners in joint Trials.
    c. Disseminate project results.

In order to achieve these objectives, five Subprojects (SPs) have been established. **SP91** ***Project Management*** is devoted to consortium level project management, and it is also in charge of the alignment of DRIVER+ with external initiatives on crisis management for the benefit of DRIVER+ and its stakeholders. In DRIVER+, all activities related to Societal Impact Assessment are part of SP91 as well. **SP92** ***Test-bed*** will deliver a guidance methodology and guidance tool supporting the design, conduct and analysis of Trials and will develop a reference implementation of the Test-bed. It will also create the scenario simulation capability to support execution of the Trials. **SP93** ***Solutions*** will deliver the Portfolio of Solutions which is a database driven web site that documents all the available DRIVER+ solutions, as well as solutions from external organisations. Adapting solutions to fit the needs addressed in Trials will be done in SP93. **SP94** ***Trials*** will organize four series of Trials as well as the final demo. **SP95** ***Impact, Engagement and Sustainability***, is in charge of communication and dissemination, and also addresses issues related to improving sustainability, market aspects of solutions, and standardization.

The DRIVER+ Trials and the Final Demonstration will benefit from the DRIVER+ Test-bed, providing the technological infrastructure, the necessary supporting methodology and adequate support tools to prepare, conduct and evaluate the Trials. All results from the Trials will be stored and made available in the Portfolio of Solutions, being a central platform to present innovative solutions from consortium partners and third parties, and to share experiences and best practices with respect to their application. In order to enhance the current European cooperation framework within the Crisis Management domain and to facilitate a shared understanding of Crisis Management across Europe, DRIVER+ will carry out a wide range of activities. Most important will be to build and structure a dedicated Community of Practice in Crisis Management, thereby connecting and fostering the exchange of lessons learnt and best practices between Crisis Management practitioners as well as technological solution providers.

Executive summary

The content and scope of this deliverable has been revised in agreement with the Project Officer and the Ethical and Society Advisory Board and thus its content does not match the description of D913.12 in the DoW.

This deliverable was originally meant to cover the fourth and final round of collected ethics approvals/notifications (i.e. data protection approvals) needed for the activities within the scope of DRIVER+. However, under GDPR it is not necessary to submit notifications/registrations to each national Data Protection Authority of data processing activities. Because of the change in regulation, it was decided to adjust the scope and objective of this current deliverable, into something more useful for the project and beyond. As a result, the deliverable documents and reflects upon some lessons learned on ethical issues related to the Trials (planning, execution and preparation). It summarizes Trial-related ethics discussions that are taking/have taken place between **WP913** ***Research Ethics & Societal impact assessments*** and the project partners and that are not captured in any other document. This document functions therefore as an interim ethical monitoring report, focusing on the Trial context. It is expected to serve as an additional reassurance to REA that the activities are monitored with regards to research ethics, especially since **WP913** ***Research Ethics & Societal impact assessments*** does not have any formal efforts to follow the Trial execution. Documenting these discussions is expected to be of added-value for the upcoming Trials, and for similar future activities beyond the project. The deliverable is structured around seven key identified issues:

1. Informed consent.
2. Having a dedicated legal/ethics expert for Trials.
3. Use of data from social media (i.e. Twitter).
4. Roles & objectivity.
5. Data storage.
6. Contribution from the H2020 data management plan.
7. Safety of participants.

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List of Acronyms

Acronym	Definition
API	Application Programming Interface
DMP	Data Management Plan
DoW	Description of Work
DPO	Data Protection Officer
ESAB	Ethical and Societal Advisory Board
FP7	Framework Program 7
GDPR	General Data Protection Regulation of the EU
H2020	Horizon 2020
IPR	Intellectual Property Rights
LSE	London School of Economics
NESH	The National Committee for Research Ethics in the Social Sciences and the Humanities
ORD pilot	Open Research Data pilot
REA	Research Executive Agency
SIA	Societal Impact Assessment
TAP	Trial Action Plan
TGM	Trial Guidance Methodology
UAV	Unmanned Aerial Vehicle

1. Introduction & Scope of deliverable

The content and scope of this deliverable has been changed in agreement with the Project Officer and the Ethical and Society Advisory Board and thus its content does not match the description of **D913.12** ***Ethical Approval*** in the DoW exactly.

This deliverable was originally meant to cover the fourth and final round of collected ethics approvals/notifications (i.e. data protection approvals) needed for the activities within the scope of DRIVER+. However, under GDPR it is not necessary to submit notifications/registrations to each national Data Protection Authority of data processing.

It might be that ethical approvals by ethical committees could be required for future DRIVER+ activities, and such approvals should still be provided if needed. In the case of participations of human subjects in some kinds of research activities, this obligation remains, irrespective of the GDPR. To identify whether approvals are still needed or not remains the responsibility of the consortium and the concerned partners, and depends on the form of activities that are carried out. E.g. in the Norwegian context the requirements for ethics approval only applies for medical or health research, and if it would be the case that such approvals are needed by partners in the project, PRIO remains available to follow-up with the concerned partners. However, as described in the DoW, PRIO's role is limited to research ethics related approvals. This means that e.g. eventual permissions from local authorities for the use of UAV or other administrative or legal approvals (beyond data protection), are outside the scope of this responsibility.

Because of the change in regulation described above, it was decided to change the scope and objective of this current deliverable. The deliverable will document and reflect upon some lessons learned on ethical issues related to the Trials (planning, execution and preparation). It will collect and summarize the most relevant Trial-related ethics discussions that are taking/have taken place and that are not captured in any other document. In a way, this document serves as an interim ethical monitoring report, focusing on the Trial context. It is expected to serve as an additional reassurance to REA that the activities are monitored with regards to research ethics. Documenting these discussions could be of real added-value for the upcoming Trials, and for similar future activities beyond the project.

During the last meeting of the Ethical and Societal Advisory Board (ESAB), held in October 2018, the suggestion to change the scope of the deliverable as described was presented, and the members of the board confirmed the legal change operated by the GDPR, and therefore welcomed the proposal to revise the scope of **D913.12** ***Ethical issues and lessons learned from Trials*** into the current format. The ESAB also highlighted the importance of generalizing and/or anonymizing the exchanges referred to in this deliverable, and thus this has been applied to the following. Following that, the suggestion was forwarded to the Project Officer, who approved the suggested approach.

1.1 Scope and ambition

Concretely, the current deliverable contains a summary of the discussions and the questions that have been set forth to PRIO, relating to the DRIVER+ Trials. Since there are two remaining Trials and a Final Demo at the point of submission of this deliverable, the document will obviously not cover all Trial-related ethics issues, but it can serve as an indicator for issues to be aware of when planning, executing or evaluating the remaining Trials and beyond the project. The document differs from the periodical Ethical Monitoring Reports in the sense that it only focuses on ethical issues that have been identified in direct relation to the DRIVER+ Trials. However, it might be that some of the issues covered in this document are still relevant and/or need further attention at the time of delivery of the next Ethical Monitoring Report (**D913.*14 Ethical Monitoring Report*** in M62).

This document also serves as a supplement to the description of the planned integration of both research ethics considerations (for the most part relating to GDPR) and the Societal Impact Assessment (SIA) methodology in the Trial Guidance Methodology (and the Training modules). This will be discussed in detail during a face-to-face meeting in Ispra, Italy in January 2019 (M57). This deliverable is also related to the advice of the ESAB during the two meetings that took place during 2018. These two meetings (January and October 2018) are both described in detail in **D913.21 *Minutes of the ESAB 1 & 2*** (1) (also submitted in M56), but the main advice and recommendations from the Board are implicitly reflected already in this report. E.g. although a focus on GDPR was a priority since early 2018, the Board advised WP leader PRIO to keep in mind also the broader research ethics issues that could be relevant for the project. Taking this into account, the following sections of this deliverable are structured around themes and issues that are broader than merely data protection issues (although this is still the main issue within the field of research ethics in DRIVER+).

The document is not meant as an evaluation of the Trials, and it does not refer to specific Trials. After advice from the ESAB, the information in this deliverable is generalized and anonymized, and this implies e.g. neither linking it to specific Trials nor revealing exchanges with identifiable individuals. By making the information and experiences general, it is expected that they are easier to relate and refer to in future activities.

1.2 Structure of the deliverable

After this introduction and some clarifications with regards to scope and ambition, section 2 is the core of the deliverable and is structured around a few key themes, each taking up one main issue that has been identified since the Trial 1 preparation started. The subsections are structured around seven key identified issues:

1. Informed consent.
2. Having a dedicated legal/ethics expert for Trials.
3. Use of data from social media (i.e. Twitter).
4. Roles & objectivity.
5. Data storage.
6. Contribution from the H2020 data management plan.
7. Safety of participants.

This deliverable does not claim to include all potential issues. This is mainly because several issues (such as GDPR recommendations and requirements) are already covered in other deliverables from **WP913 *Research ethics & Societal impact assessments***, such as **D913.13 *Ethical Monitoring Report 3*** (2) and **D913.21 *Minutes of ESAB meeting 1 & 2*** (1). Following the feedback from the 5th technical review meeting in Brussels, a clear attempt has been made to avoid redundancies in the deliverables from **WP913 *Research ethics & Societal impact assessments***. Rather, the current deliverable focuses on the Trials, and the ambition is not only to feed information and recommendations into the remaining DRIVER+ Trials, but also to present a document with general lessons learned and key discussions that have in some way or another been necessary for the DRIVER+ Trials, and that is expected to be relevant for the future use of the DRIVER+ sustainable output.

In Annex 2, the current version of the informed consent form that have been prepared and offered to the Trial committees (as well as for any other relevant activity) is attached. The idea is that this form can be adapted and scaled to the different Trials, depending on several features of that Trial (such as the extent of involvement of external participants, the types of data collected, etc.). For some activities, only a basic form is needed, but for the more complex activities, e.g. with unaffiliated volunteers participating in field exercises, more comprehensive information should be given, and consent should be sought.

2. Key ethics issues relating to the DRIVER+ Trials

The following core section lists some of the most relevant emerging ethical issues relating to the DRIVER+ Trials, as identified by **WP913**. The information that this section is based on results from various sources, such as discussions during project meetings, issues identified in the ethical monitoring questionnaires which provided the base for **D913.13** ***Ethical Monitoring Report 3*** (2), one-on-one consultations initiated by individuals or organizations taking various roles within the Trials, and other kinds of follow-up between PRIO and the project partners. Section 2 is structured around seven subsections, each describing one key issue. Section 2.1 will start off with describing the informed consent which is still considered to be the most important issue for all Trial related activities within the scope of **WP913** ***Research ethics & Societal impact assessments***. This is relevant for all Trials and all activities where human participants are included. The concept of informed consent has already been described in several deliverables within DRIVER+ such as **D91.3** ***Ethical Procedures, Risks and Safeguards*** (3) and **D913.13** ***Ethical Monitoring Report 3*** (2) but, based on some new insight specifically in relation to the planning and execution of the subsequent Trials, this issue will be given some additional attention in this report.

2.1 Informed consent

Problems can occur if the methodological requirements for research activities that include human individuals come into conflict with the requirement of informed consent (4 p. 32). Under the GDPR, processing personal data is generally prohibited, unless it is explicitly allowed by law or if the data subject has consented to the processing. The challenges of informed consent are widely known in the academic environment, and common issues are e.g. the detail level and amount of information disclosed to the participants in advance, the timing of distributing such a form, and how to ensure consent when the number of participants is very high. Early in the project a template was prepared so that partners could use it for any project activity (this was delivered with **D95.21** ***Ethical Monitoring Report 1*** in M12) (5), and several updates have been made to the template since.

The concept of informed consent has been a recurring issue since the beginning of the project. On the one hand, partners are eager to follow best practice, e.g. to make use of robust and informative informed consent forms, although the procedure might be experienced as a heavy administrative burden – if participants must ask their organizations for permission to participate in e.g. interviews, this could mean administrative delay. On the other hand, discussions have been taking place between project partners and PRIO where the sentiment towards the use of such forms has been explicitly negative. It should be stated that these issues have been solved in a way that they did not pose any risk to the quality of the project, but PRIO does think it is worth mentioning this in this deliverable, so that it can be enforced maybe on an even earlier stage for such activities in the future. Already in the first Ethical Monitoring Report (submitted in April 2015), partners expressed that the "formalization of ethics", which informed consent could be interpreted as a part of, was challenging (5 p. 30). As expected, the guidance did become more operational, and the current versions of the informed consent forms are – although extensive – developed so that only relevant information can be included, and irrelevant boxes and considerations can simply be deleted before the form is distributed to the participants.

The concept of informed consent has been a recurring issue since the beginning of the project. On the one hand, partners are eager to follow best practice, e.g. to make use of robust and informative informed consent forms, although the procedure might be experienced as a heavy administrative burden – if participants must ask their organizations for permission to participate in e.g. interviews, this could mean administrative delay. On the other hand, discussions have been taking place between project partners and PRIO where the sentiment towards the use of such forms has been explicitly negative. It should be stated that these issues have been solved in a way that they did not pose any risk to the quality of the project, but PRIO does think it is worth mentioning this in this deliverable, so that it can be enforced maybe on an even

earlier stage for such activities in the future. Already in the first Ethical Monitoring Report (submitted in April 2015) partners expressed that the "formalization of ethics" was challenging, of which informed consent could be interpreted as being a part of. As expected, the guidance did become more operational, and the current versions of the informed consent forms are – although extensive – developed so that only relevant information can be included, and irrelevant boxes and considerations can simply be deleted before the form is distributed to the participants.

> *For consent to be informed and specific, the data subject must at least be notified about the controller's identity, what kind of data will be processed, how it will be used and the purpose of the processing operations as a safeguard against 'function creep'. The data subject must also be informed about his or her right to withdraw consent anytime. The withdrawal must be as easy as giving consent. Where relevant, the controller also has to inform about the use of the data for automated decision-making, the possible risks of data transfers due to absence of an adequacy decision or other appropriate safeguards* (6).

Depending on the nature of the activity and the data processing, the informed consent form can be adjusted, but the basic requirements as per GDPR listed in the quote above are minimum. Where relevant, the controller must also inform about the use of the data for automated decision-making, the possible risks of data transfers due to absence of an adequacy decision, or other appropriate safeguards. The signed form should clearly state e.g. if images and/or videos from the Trial will be shared in social media. To summarize, the informed consent form should minimally include:

Table 1 Requirements for informed consent

Basic requirements for informed consent	Consent must also be..
The data controller's identity	Informed, freely given and specific
What kind of data will be processed	Bound to specific purposes that are explained
How the data will be used	Preferably written
What the purpose of the processing is	In clear and plain language
A statement that the consent can be withdrawn	Unambiguous and explicit

Based on this, as per M56, the informed consent form template has been adjusted, and can be found in Annex 2 of this deliverable. However, in addition to informed consent, there are five other legal bases for processing personal data, and if there are cases where personal data is collected, but informed consent cannot be obtained, the legally responsible unit for the data collection needs to make it explicitly clear how the processing adheres to at least one of the other five bases. The others are: contract, legal obligations, vital interests of the data subject, public interest and legitimate interest, as stated in Article 6(1) GDPR. Specifically, informed consent should be signed before the data collection takes place. For the DRIVER+ Trials, this would e.g. mean that external participants (such as volunteers) should sign before they can physically take part in Trial activities. Usually, this would mean before Dry Run 2. Furthermore, for solution providers, if no personal data is collected from them non-disclosure agreements, confirmation of commitment or other forms of documents regulating issues such as Intellectual Property Rights (IPR) and copyright should suffice.

Finally, it should be noted that informed consent has several advantages beyond adhering to the law. E.g. it creates mutual trust between the researcher and the participant, it might make the participants even better suited to participate in the Trial because they know more about the conditions and the aims, the format of the Trial and the expected outputs of the activity. It also allows the DRIVER+ Trial organizers to take better care of the participants, and it reduces the liability exposure of Trial organizers by establishing and maintaining communication channels where potential conflicts can be resolved with reference to a written document. This kind of formal regulation is not only established to protect the participants in the

DRIVER+ activity, but also to help the Trial organizer: information empowers the participant, and consent empowers the researcher.

2.2 Dedicated legal/ethics expert for Trials

The responsibility for ensuring legal compliance from a professional point of view lies with each legal entity/project partner in charge of the activity. Although there has been no budget for this in the current setup of the DRIVER+ project and the Trials, for future users of the DRIVER+ legacy, it might be worth investing in having a dedicated expert on legal and ethical issues. The role of this individual, which could also be externally hired with no stake in the Trial activities, could be to analyse the information entered in the Trial Action Plan (TAP), e.g. to see what kind of solutions have been selected, what format the Trial is planned to take (table-top, field Trial, etc.), if/how external participants/volunteers are involved, and to help with getting the right approvals/templates. In addition, the relevant national supervisory authority in the country where the Trial is taking place can be contacted for GDPR specific issues. Such a unit exists in all EU member states.

Within the scope of the DRIVER+ project, the role of **WP913** ***Research Ethics & Societal impact assessments*** has been limited to research ethics in the sense of collecting the required authorizations and notification for project activities, as well as informing and advising project partners about research ethics. However, outside the context of a research project, it might be likely that an expanded role is necessary, and the idea of appointing a representative for these key issues seems sensible. Of course, depending on the scope and the nature of the Trial, the scope of the role should be adjusted to the different activities/Trials. Having such a representative could not only ease the implementation of the necessary requirements and best practice guidelines for a Trial, but also serve as a very useful dedicated resource in the evaluation of a Trial. While the legal departments of partners in the project have been consulted during the project, e.g. for GDPR compliance, a dedicated individual with efforts to follow the actual execution of the Trials would be beneficial.

2.3 Use of data from social media (i.e. Twitter data)

Social media solutions are very likely to be part of the DRIVER+ Portfolio of Solutions and are likely to be tested in the Trials as well as beyond the project. These kinds of solutions pose new challenges as well as opportunities, and some of these are described in the following. Some issues have already been identified during the project, while others refer to potential issues that should be taken into account for the future. In the meeting held in October 2018, the ESAB underlined the importance of following closely the guidelines for internet-based research (such as those formulated by the NESH (7)), thus some experiences from the project, as well as some issues to pay attention to in the future, are included in the following. It might be that these considerations and concerns seem exaggerated in the context of DRIVER+. However, reflecting on the types of issues described in this subsection is important and will improve the quality of the research activity/Trial as those issues can be generalized to social media beyond Twitter. Furthermore, they indicate an expected development which shows that research on/with social media is becoming increasingly common, and thus deserves close attention.

Social media refers to websites and applications “that enable users to create and share content or to participate in social networking” (8). This section will not discuss the facilitation of research being done using online solutions (e.g. hosting anonymous group interviews online), but rather focus on the use of social media as a source of what might be called naturally occurring data. Data mining involves “examining large sets of pre-existing data to produce new information” (8) and this can be applied to research aiming to understand attitudes, opinion and trends and in some cases also to forecast future behaviour. Twitter is a highly popular source for harvesting this kind of data, and the use of Twitter for this purpose is growing.

According to a report by Beninger et. al (9 p. 5), the use of data mining of tweets to better understand complex social issues has been growing in popularity. Specifically, the authors highlight that data mining "is of particular value in crisis situations such as the 2011 riots in England" (10), and mentioned how "researchers conducted an analysis of a database of more than 2.5 million riot-related tweets to explore the role of social media in the riots. The corpus of Twitter data complemented depth interviews used to provide a rich understanding of who was involved and what their motivations were" (9). While these kinds of platforms offer great possibilities for research, there are several methodological and ethical challenges and pitfalls that should be reflected upon and mitigated to the extent possible. Part of the challenge is to make sure that the datasets still can be used within reasonable time after the evaluations to infer meaning from, and to ensure that the context of the online posts are considered. While formal guidelines are largely missing for this kind of research, a general rule of thumb has been to apply the same standards and the same procedures to this kind of research as you would do for traditional data collection methods.[1] In addition, the provisions in GDPR should always form the basis.

If solutions taking place on/with social media are to be tested in Trials, there are a few issues that should be considered. There are various legacy systems (software/process) that can be used for social media analysis, and each of these might have implications that should be investigated in each individual case. E.g. it might be that to test such solutions in a realistic way, acquiring realistic data (e.g. Twitter messages posted during a real-life crisis) would be necessary. Some considerations and ethical implications with regards to potential ethical issues that are of a more general nature are described in the following.

With regards to collecting data from Twitter, there are four main ways of doing this:

1. Retrieve from the Twitter public API.
2. Find an existing Twitter dataset.
3. Purchase from Twitter.
4. Access or purchase from a Twitter service provider.

Each of these have implications, and a key question that an organization should reflect upon when considering to trial a solution that has these features are e.g. do you know exactly how you want to acquire and use the data? From a research ethics point of view, it would also be important to consider and determine issues like e.g. validity, and if a complete dataset is needed (i.e. every tweet that meets criteria) or if an incomplete or sampled dataset is acceptable. With regards to potential legal issues, it is recommended to consider the following: Sharing of datasets is prohibited under Twitter's API (Application Programming Interface) terms of service. However, researchers can share the tweet identification numbers, associated with each tweet, which can be used by other researchers to obtain Twitter datasets (11). If, for any reason, it is not possible to share tweet IDs then sharing the keywords and retrieval time of the data may allow researchers to obtain a similar dataset. There may also be specific requirements for producing tweets within a publication i.e. following Twitter guidelines[2].

Like all research, social media research is full of ethical dilemmas that should be carefully considered before starting any research activity. According to the report by Beninger et. al, the views of users are often missing from the conversation (9). How do they curate their digital lives? What do they understand about how their information is used and shared on the internet? What do users think about their information

[1] An example of guidelines has been published by the Norwegian National Committee for Research Ethics in the Social Sciences and the Humanities (NESH). It contains many universally relevant considerations, and can be accessed here: https://www.etikkom.no/globalassets/documents/english-publications/ethical-guidelines-for-internet-research.pdf.

[2] See https://dev.twitter.com/terms/api-terms, Twitter's API terms of service.

being used by researchers and in online and social media research? Among the findings by Beninger et. al, were the fact that the participants in the study expressed concern about the quality of social media research and these concerns can be grouped under the research principles of validity and representativeness. E.g. these concerns included:

- People behave differently online and offline and so online research could not reflect the "real world".
- Exaggerated views were a result of the anonymity the internet afforded and therefore research findings using views from online sources would lead to inaccurate conclusions about something or someone.
- Impulsive comments posted online may result in researchers using a view that does not accurately reflect someone's "normal" viewpoint but instead only something they held for a moment in time.
- Inaccurate profiles taken without further context would lead to inaccurate information and findings[3].

With regards to consent and anonymity, we can say that the context of the research plays a key role (i.e. what the topics of the tweets are), but that it is always better to err on the side of safety. An acceptable way of being able to disregard informed consent could be to anonymize (to not quote a username alongside a post). The advantages with obtaining informed consent, in addition to being a moral and legal requirement (as per GDPR), is that it can help guarantee that the user has not changed his or her opinion since the post.[4] It is also useful in order to tell the users/data subjects about the research context and the nature of the research that they are represented in.

If the idea is to gather real data from Twitter users during an actual crisis in a specific location, country, city, etc. it would be important to clarify what this kind of data can and cannot tell us/or analysis. It is recommended to anonymize all the Twitter users, unless it can be argued and justified why anonymization is not the best option. When collecting data from large datasets it might be impossible to obtain informed consent from all participants, but if specific tweets are reproduced in an academic publication, informed consent should be obtained. This is especially important if the data (i.e. the tweet) is considered sensitive.

With regards to retrieving the Twitter datasets, there are a few issues that should be considered. Use of certain keywords or hashtags may not retrieve all the data related to a certain topic. One way to mitigate this it to identify as many search queries as possible in advance, and to filter the dataset for non-relevant tweets after the data has been retrieved. As highlighted by e.g. Wasim Ahmed, there is a risk that missing certain keywords or hashtags could introduce a systematic bias, which would lead to a biased sample (11).

Another issue to keep in mind is language. Datasets are also likely to be limited by the language that is used to retrieve data, e.g. using the English keyword *fire* to retrieve data related to a forest fire in Portugal will not gather data from other countries tweeting or in other languages about the fire, which may use a different keyword i.e. a different language. Depending on the nature of the Trial activity, it might be relevant to include multiple languages in the data collection phase. If it is not possible, a basic recommendation would be to reflect upon this potential limitation in the analysis of the datasets.

[3] The report by NatCen authored by Kelsey Beninger, Alexandra Fry, Natalie Jago, Hayley Lepps, Laura Nass and Hannah Silvester in 2014 can be accessed here. The bullet point list referred to above is quoted from page 2 of the report. http://www.natcen.ac.uk/media/282288/p0639-research-using-social-media-report-final-190214.pdf.

[4] As per Art. 16 GDPR the data subject has the right to obtain from the controller without undue delay the rectification of inaccurate personal data concerning him or her, which could be the case if inaccurate data that is not up to speed is being processed.

Another issue relates to spam. If there are a lot of tweets during a specific crisis, there is a risk that this can be misused in the sense that there can be a large amount of so-called link-baiting in popular hashtags (i.e. tweets designed for the users to click to be taken to a non-relevant website), and popular topics on Twitter can attract a large amount of spam. Assurance that users, which the tweets are retrieved from, are not fictitious should be built into the methodology.

A final issue has to do with representability. A key point to include in the research method, when using e.g. Twitter data is the fact, that Twitter users are not representative for the offline population. They are not even representative of the totality of Internet users or even Twitter users (since not all Twitter users will tweet on a certain topic). One can also say that relying on information from Twitter should take into account that since what motivates people to tweet or not can vary greatly. The tweets are not representative for the general opinion of the population, even if the number of likeminded opinion tweets is large. (12)

2.3.1 Public versus private data?

One question that has been briefly discussed in DRIVER+ is the issue of whether or not publicly available data can be used freely and without consent. A common impression seems to be that information that has been published online so that anyone can see it, is free to use for research purposes. While this is to some extent acceptable, there are some complicating factors that one should be aware of. E.g. it is important to balance the use of materials from open forums freely without consent against the requirement of respect for individual's privacy and close relations (7). In practise, this can be difficult since it is not always so clear what is to be considered public or private arenas, and there might be a difference between what people view as private and what is technically available online. In other words, just because information is published online does not necessarily allow using it freely. Two examples are given in a set of ethical guidelines for internet-research by the National Committee for Research Ethics in the Social Sciences and the Humanities (NESH):

> *Some people view a personal blog as a public arena, while others consider the blog as publicly-available, but with private content. Different participants on an Internet forum may have differing views of what is private and public, and their patterns of communication and behaviour will be influenced by this view* (7 p. 4).

To safeguard the research subject's integrity, the researcher should take the "integrity of the context" into account (7 p. 4). This means not assuming that all users of the internet have a conscious view or knowledge about which parts of what they publish are public or not. E.g. the knowledge about personal data settings on your various social media accounts should be expected to vary greatly.

In terms of legal considerations, e.g. data extracted from the Twitter APIs contain personal information meaning they are subject to relevant data protection legislation (GDPR). In cases where informed consent cannot be sought from users (likely to be most of cases if thousands of posts are being subject to analysis), the key requirement is that the researcher should establish the fair and lawful basis for collecting personal information. A researcher can accept that the terms of service of social media networks provide adequate provision to cover this aspect of the GDPR (although there are some caveats such as if the data has been collected using a service that provides additional meta data on users, such as sensitive data) (13).

2.4 Roles and objectivity

To make sure that the Trials are executed in the most scientifically sound way, the roles of the different participants should be carefully considered. These considerations should relate to such issues as potential biases and level of preconceived knowledge, the role of the participant in the design of the Trial or the TGM, the scenarios, etc. versus the role during the actual Trial. Reflections should be made about how to ensure as much objectivity as possible, e.g. for someone knowing the Trial setup in advance. There are no

given answers to this, since it will depend on several factors in each specific case, but it is recommended that this is taken into account in the Trial execution and evaluation. E.g. for being an observer during the Trial, the issue could be relevant to consider. The concern of unconsciously influencing the actors during the Trial touches upon some very fundamental research ethics issues, that is relevant in many situations, such as when doing interviews. While it is hard to fully mitigate this risk, being aware of it in the first place is already good, and although there might not be a universal definition of the requirements for being a formal observer in a Trial, the choice should likely come with a disclaimer stating previous roles, preconceived knowledge about the scenario, affiliation with organizations in the Trial, etc. E.g. in the analysis part of the observation documentation, this point could be highlighted. However, in terms of trialling out also e.g. the TGM including these kinds of reflections could also be considered as useful outputs (and inputs to the later Trials).

In the context of the Trials in DRIVER+, another issue relates to the fact that some partners participating in the Trials have in fact different roles at the same time. In the DRIVER+ Trial context, the constellation of the consortium naturally sets some limitations with regards to the roles of the Trial participants. E.g. one partner might be Solution Coordinator or Trial Owner (as part of the Trial Committee and responsible for the final solution selection) and potential solution provider at once. Although this latter issue relates to questions beyond the scope of this deliverable (e.g. Trial objective, the chosen methodology, available resources), a basic recommendation with regards to research ethics would be to include reflections about the eventual dual roles of particular partners in the evaluation of the Trial. By explaining and being transparent about the potential limitations that such a duality could include with regards to e.g. validity, the value of the Trial outcome would likely increase.

To make sure that the Trials are executed in the most scientifically sound way, the roles of the different participants should be carefully considered. These considerations should relate to such issues as level of preconceived knowledge, the role of the participant in the design of the Trial or the TGM, the scenarios, etc. versus the role during the actual Trial. Reflections should be made about how to ensure as much objectivity as possible, e.g. for someone knowing the Trial setup in advance. There are no given answers to this, since it will depend on several factors in each specific case, but it is recommended that this is taken into account in the Trial execution and evaluation. E.g. for being an observer during the Trial, the issue could be relevant to consider. The concern of unconsciously influencing the actors during the Trial touches upon some very fundamental research ethics issues, that is relevant in many situations, such as when doing interviews. While it is hard to fully mitigate this risk, being aware of it in the first place is already good, and although there might not be a universal definition of the requirements for being a formal observer in a Trial, the choice should likely come with a disclaimer stating previous roles, preconceived knowledge about the scenario, affiliation with organizations in the Trial, etc. E.g. in the analysis part of the observation documentation, this point could be highlighted. However, in terms of trialling out also e.g. the TGM including these kinds of reflections could be considered as useful outputs (and inputs to the later Trials).

Personal data is collected in the DRIVER+ Trials, and it is very likely that personal data will be collected by those parties eventually utilizing the DRIVER+ outputs beyond the project. The GDPR does not give a clear statement on how long you can store personal data. Rather, best practises for storage must be assessed by the data controller in individual cases, based on data minimization principles, etc. Outside health research, there is no longer a notification or licensing obligation for processing personal data, which means that the data controller is solely responsible for ensuring that the data is well protected. The data protection officer (DPO) or similar at the responsible institution should be contacted if the Trial owner has questions about storing data.

Openness in research is essential for quality assurance of research and for the research to benefit individuals, groups and communities. Major European and national initiatives are ongoing to make available and share data (Open Science). Basically, there seems to be fundamental contradictions between the principle of data minimization, as found in GDPR, and the value of producing and circulating data, as found in various Open Science initiatives. This requires ethical reflection about the value of data produced

and whether and how they can be transferred to other forms of data (e.g. pseudonymized).[5] The responsibility of secure data storage belongs to the data controller, and by following basic data protection principles (described already in **D91.3 *Ethical guidelines, risks and safeguards*** (3)) such as only collecting data you need, would mean that there is less data to secure. Furthermore, obtaining informed consent from participants would oblige the data controller to already reflect on and plan for secure data storage, since this should be part of the information given to participants.

2.5 Inputs from the H2020 Data Management Plan

The so-called Data Management Plans (DMPs) are a key element of good data management under H2020. Although DRIVER+ was funded under the FP7 program, the guidelines on the DMP for H2020 contains very useful setups for managing data in a context beyond the project duration.

A DMP is a living document (which becomes increasingly detailed throughout the project) which describes the data management life cycle for the data to be collected, processed and/or generated by a H2020 project[6]. As part of making research data findable, accessible, interoperable and re-usable (FAIR), a DMP should include information on:

- The handling of research data during & after the end of the project.
- What data will be collected, processed and/or generated.
- Which methodology & standards will be applied.
- Whether data will be shared/made open access.
- How data will be curated & preserved (also beyond the lifetime of the project).

A DMP is required for all projects participating in the extended ORD pilot, unless they opt out of the ORD pilot. In Horizon 2020 the Commission committed itself to running a flexible pilot on open research data (ORD Pilot). The ORD pilot aims to improve and maximise access to and re-use of research data generated by a Horizon 2020 project. However, projects that opt out are still encouraged to submit a DMP on a voluntary basis. For future use of the DRIVER+ outputs, the implementation of DMPs should be considered. Managing research data in a good way is not a goal in itself, but it should e.g. serve to simplify the inclusion of external participants in the research activities (by having the information for the informed consent forms already prepared), as well as help the people and organizations responsible for data collection and data processing in keeping the overview of the various data sets that are present in the project, and how they will be used. Ultimately, this will also help with ensuring that individual data protection rights are upheld, e.g. referring to right of access by the data subject (as per Art. 15 GDPR). In sum, although such an approach will not be required from users of the DRIVER+ results, formalizing data management in the way that a DMP allows for from the very onset of the activity is expected to have value for the Trial planning, execution and evaluation. In other words, although it will not be mandatory for users of e.g. the TGM beyond the project to set up a DMP (unless it does happen in the format of a H2020 project), the requirements and the structure of the DMP within H2020 could serve as good guidelines/indication for how to manage data during such activities.

[5] The content of this subsection is largely based on the recommendation by the Norwegian National Research Ethics Committees, available in Norwegian at: https://www.etikkom.no/Aktuelt/gdpr-og-forskning/.

[6] The information about DMPs are derived directly from http://ec.europa.eu/research/participants/docs/h2020-funding-guide/cross-cutting-issues/open-access-data-management/data-management_en.htm.

2.6 Safety of participants

If a research project or a research activity is to be deemed ethical it needs to avoid undue harm to the participants.

The use of scenarios as a way of trialling out crisis management solutions is a significant part of DRIVER+ and to not be able to give *full* insight in what the scenarios will consist of to the participants/researchers/volunteers beforehand is generally not a problem (based on the knowledge about the DRIVER+ Trials at this point in time). In fact, to only provide the necessary amount of information to a participant in the preparation of a Trial can be necessary in order to perform this kind of activity, since an element of surprise might be crucial to keep it realistic. The key principle in these reflections is *proportionality*, and the problematic issue only appears if participants are in fact being put at risk of physical or mental harm during the Trials. It could be seen as unethical if there is a real risk of the participants having chosen to back out of the activity when the nature and content of the Trials (or Trial scenarios) had been known to them in advance. The main recommendation in this regard is, that as much information as possible should be given to the participants beforehand without compromising the foundation of aim of the methodology.

There is also a difference between Trials that are table-top and Trials with a field component. E.g. a general introduction to the volunteers before the Trial could state that the participants should be careful navigating in a steep terrain or to wear protection gear to protect them from snakes or ticks or similar, without compromising the aim of the Trial. If the risk of injuries or mental harm are considered to be higher for upcoming Trials or Trials beyond DRIVER+, but they are still within an acceptable level of risk, more detailed informed consent should be sought, and more information should be given to the participants in advance. The remoteness of the "field component" of the Trial also plays a role here, e.g. in terms of internet connection and possibilities to call for assistance if needed. For a table-top Trial, it would be relevant to inform participants about the relevant safety measures at the location of the Trial, such as fire exits and what to do in case of a crisis such as a fire.

For most of the Trial activities, the potential risks of the expected activities are mainly possible physical injuries that are not to be considered any more risky than everyday activities like riding the bus to work. This can include risks such as tripping, being hit by falling luggage, or squeezing your fingers in the bus door. For trialling solutions regarding psycho-social support/psychological first aid (PFA) or similar, there might be other ethical implications that need to be considered, as far as they can pose a risk to the mental health of the participants. It should be absolutely clear that it is unethical to put practitioners in a possibly trauma-causing situation in a Trial context, so any risk – physical or mental – should be actively minimized. Including a KPI on safety could be one way of making sure that the issues above are actively taken into account.

3. Way forward

Although some key ethical issues and lessons learned from the Trial activities have been described in this report, additional issues are likely to emerge in the future. These will be documented in the fourth ethical monitoring report, and followed up on accordingly. In addition, issues will be taken up with the ESAB. The issues described in this report are not critical to the project, and the ESAB stated that the challenges the project has faced have not been of an ethical nature (see **D913.21** ***Minutes of ESAB meeting 1 & 2*** (1)). However, following best practice for research ethics means not only to act reactively to emerging issues, but also to proactively anticipate future challenges. This deliverable has aimed at doing both, and **WP913** ***Research ethics & Societal impact assessments*** remains available for guidance and support in individual cases, as far as this deliverable is expected to also raise questions and stimulate exchanges of how to integrate and implement research ethics into the project and beyond, in the best possible way.

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Annexes

Annex 1 – DRIVER+ Terminology

In order to have a common understanding within the DRIVER+ project and beyond and to ensure the use of a common language in all project deliverables and communications, a terminology is developed by making reference to main sources, such as ISO standards and UNISDR. This terminology is presented online as part of the Portfolio of Solutions and it will be continuously reviewed and updated[7]. The terminology is applied throughout the documents produced by DRIVER+. Each deliverable includes an annex as provided hereunder, which holds an extract from the comprehensive terminology containing the relevant DRIVER+ terms for this respective document.

Table A1: DRIVER+ Terminology

Terminology	Definition	Source
Data protection approval	Procedure of applying to the national or local Data Protection Authority to report about the collection, storage and/or analysis of personal data for a specific task. Whether reporting the activity is enough or actual approval is granted depends on the respective data protection authority. The task leader is generally the legal owner of this procedure.	Initial DRIVER+ definition.
Data, personal	Information relating to an identified or identifiable individual that is recorded in any form, including electronically or on paper.	ISO/IEC TR 24714-1:2008(en) Information technology — Biometrics — Jurisdictional and societal considerations for commercial applications — Part 1: General guidance, 2.9.
Evaluation	Process of estimating the effectiveness, efficiency, utility and relevance of a service or facility.	ISO 5127:2017(en) Information and documentation — Foundation and vocabulary, 3.1.3.02
Key Performance Indicator (KPI)	Key performance indicator (KPI) is a quantifiable measure that an organization (person or group of people that has its own functions with responsibilities, authorities and relationships to achieve its objectives) uses to gauge or compare performance (measurable result) in terms of meeting its strategic and operational objectives (result to be achieved).	ISO 22300:2018.

[7] The Portfolio of Solutions and the terminology of the DRIVER+ project are accessible on the DRIVER+ public website (https://www.driver-project.eu/). Further information can be received by contacting coordination@projectdriver.eu.

Terminology	Definition	Source
Lessons Learned	Lessons learning: process of distributing the problem information to the whole project and organization as well as other related projects and organizations, warning if similar failure modes or mechanism issues exist and taking preventive actions.	ISO 18238:2015(en) Space systems — Closed loop problem solving management, 3.3.
Research ethics	The ethics of the planning, conduct, and reporting of research; this pertains in particular to rules and guidelines for the participation and protection of individuals taking part in the research activities.	Initial DRIVER+ definition.
Trial	An event for systematically assessing solutions for current and emerging needs in such a way that practitioners can do this following a pragmatic and systematic approach.	Initial DRIVER+ definition.
Trial Action Plan (TAP)	The main Trial planning document, facilitating collaborative planning and supporting execution of the Trial. It covers all areas related to the Trial organization and is used to record efforts, circulate decisions and assess progress.	Initial DRIVER+ definition.
Trial Guidance Methodology (TGM)	A structured approach from designing a Trial to evaluating the outcomes and identifying lessons learned.	Initial DRIVER+ definition.
Volunteer	Individual, who is not affiliated with an existing incident response organization or voluntary organization but who, without extensive preplanning, offers support to the response to, and recovery from, an incident.	ISO 22319:2017(en) Security and resilience — Community resilience — Guidelines for planning the involvement of spontaneous volunteers, 3.1.

Annex 2 – informed consent form prepared for the Trials (version of December 2018)

THIS PAGE CONTAINS INFORMATION MEANT FOR THE LEAD RESEARCHER/THE PERSON(S) RESPONISBLE FOR OBTAINING INFORMED CONSENT. THIS PAGE SHOULD NOT BE DISTRIBUTED TO THE PARTICIPANTS!

The next pages contain a best practise template for information sheet and informed consent, which can be adapted to and used for any project activity. The template is designed in such a way that it can be used both for more regular research activities, as well as for the Trials, and also those with a field component. While obtaining informed consent is mandatory, as per basic research ethics guidelines, the use of this exact template is not. However, since DRIVER+ aims to ensure best practise in this regard, PRIO (as responsible partner for WP913) recommends that the template and the guide included in the template is used.

"Informed consent" means that the participant is made aware of all possible uses that may be made of the data collected from her/him. The participant should also be correctly informed about the purpose of the study and the procedures the researcher is adopting.

Please confirm whether or not you are obliged to follow particular national guidelines for application provided by your local Data Protection Authority or other authorities.

Any questions about this template can be directed to (Name of lead researcher) at (Lead researchers email address).

If there is information in the form that are deemed not relevant for the activities for which it is being used, this information can be deleted. However, be aware that there are some basic requirements that should always be included, as per Art. 6 GDPR:

For consent to be informed and specific, the data subject must at least be notified about the controller's identity, what kind of data will be processed, how it will be used and the purpose of the processing operations as a safeguard against 'function creep'. The data subject must also be informed about his or her right to withdraw consent anytime. The withdrawal must be as easy as giving consent. Where relevant, the controller also has to inform about the use of the data for automated decision-making, the possible risks of data transfers due to absence of an adequacy decision or other appropriate safeguards.

Further, when adapting the template to the relevant activity, please keep the following in mind:

The informed consent form should generally be written in lay terms. Consider the audience before adapting the form to the appropriate reading level. Use active voice whenever possible. Avoid abbreviations and acronyms that are not self-evident to the participant.

A copy of the form should be given to the participants to take home with them.

NB! Since copyright laws (which define the scope of intellectual property rights) vary across jurisdictions, and company policies vary between organizations, and since these issues are outside the scope of PRIO's responsibility in DRIVER+, no further guidelines are given here, but should rather be investigated in each individual case depending on need.

INFORMATION LETTER AND CONSENT FORM

You have been invited to participate in research as part of the DRIVER+ project. The project started in May 2014 and will last until April 2020. TNO is the coordinator of the project, and can be contacted at the following address: coordination@projectdriver.eu. The rest of this document will inform you about the details of your participation, and at the end you will be asked to consent to participating. The consent relates to research conducted within the FP7-funded project DRIVER+ *Driving Innovation in Crisis Management for European Resilience*, and a description of the overall project objectives is given below.

General information about the research project you are participating in

Current and future challenges due to increasingly severe consequences of natural disasters and terrorist threats require the development and uptake of innovative solutions that are addressing the operational needs of practitioners dealing with Crisis Management. DRIVER+ (Driving Innovation in Crisis Management for European Resilience) is an EU FP7 Crisis Management demonstration project aiming at improving the way capability development and innovation management is tackled.

The research project has three main objectives:

1. Develop a pan-European Test-bed for Crisis Management capability development:

a. Develop a common guidance methodology and tool (supporting trials and the gathering of lessons learned
b. Develop an infrastructure to create relevant environments, for enabling the trialing of new solutions and to explore and share CM capabilities
c. Run trials in order to assess the value of solutions addressing specific needs using guidance and infrastructure
d. Ensure the sustainability of the pan-European Test-bed

2. Develop a well-balanced comprehensive Portfolio of Crisis Management Solutions:

a. Facilitate the usage of the portfolio of solutions
b. Ensure the sustainability of the portfolio of tools

3. Facilitate a shared understanding of Crisis Management across Europe:

- Establish a common background
- Cooperate with external partners in joint trials
- Disseminate project results

Background and purpose of the research

The research under the lead of focuses on Add activity and is embedded in the DRIVER+ project.

<DESCRIBE IN A FEW SENTENCES THE FOLLOWING:

- **What you do in the planned research (if you have, add a research question)**
    - **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.**
    - **For Trials with a field component, it is especially important to give as much information to the participants as possible in advance.**
- **Why you do it, and what is the purpose for (in plain language)**
- **How the data will feed into the DRIVER+ project**
- **What are reasonable benefits to society for completing this research (i.e. we hope that the information we get from completing this research will help us better understand "x")>**

Selection of participants and treatment of data

<DESCRIBE IN HALF A PAGE THE FOLLOWING:

- **Your sample (how many participants)**
- **On what basis you chose the participants**
- **How you contacted the participants**
- **What exactly you want the participants to do/answer/talk about**
- **What kind of data will be collected and how (e.g. length/format of interviews, conditions of observations, time commitment for surveys, collection of personal records, time commitment and selection procedures for focus groups, equipment used for recording of sounds or images, video etc.)**
- **Whether and how the data will be recorded, transcribed, encrypted or anonymized**
- **How the data will be stored, where, and for how long**
- **When the data will be destroyed**
- **If the data will be shared, and with whom**
- **How the data will be processed, analysed, who will have access to and responsibility for it**

Voluntary 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 ***<ADD ACTIVITY>*** 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>***.

Confidentiality and anonymity

Specify how the research will be used, e.g. research articles, presentations, project reports. Indicate as far as possible if individual participants may be identified in any of the uses.

Make a statement that data and personal information of the participants should remain confidential, unless there is a clear reason for it to be public, and indicate who will have access to the data. For example:

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 will duly respect this.
<DESCRIBE WHO HAS ACCESS TO DATA.>

- **Indicate to what extent anonymity can be guaranteed – (e.g. anonymity cannot be guaranteed in group context) and whether participants will be identified or not in the dissemination of the research.**
- **Give a description of the safeguards in place for securing the data (e.g. that data are to be kept in a secure place for a minimum of X years following completion of research project, indicate if electronic data will be password protected or encrypted) and when the data will be destroyed in a way that ensures privacy and confidentiality.**
- **Indicate if the participant will receive a copy of e.g. a report of the research findings.**
- **(If applicable) If there is a possibility that you may use the data from this study, in future unspecified research projects – this should also be communicated in this section (i.e. PARTNER X may use the data we get from this study in future research, but if we do this it will have to be approved by a Research Ethics Committee.)**

Further information

By signing this form you agree not to share pictures, films or other information about the **<ADD RESEARCH ACTIVITY>.**

<ADD A FEW SENTENCES ABOUT INSURANCE, IF APPLICABLE> E.g. I have been informed that insurance responsibility of the organizer is only up to the insurance value. The DRIVER+ consortium partners and organizers will not accept any liability for any loss of life, personal injury or property damage. Attendees are to make their own arrangements for appropriate insurance cover for during the **<ADD ACTIVITY>**

<ADD A FEW SENTENCES ABOUT COPYRIGHT/IPR, AS RELEVANT> Attempt to use lay terms, and describe the conditions in clear words to the participants.

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 **<NATIONAL DATA PROTECTION AUTHORITY>**.

Kind regards,

<SIGNATURE LEAD RESEARCHER)>

<ADD CONTACT DETAILS OF LEAD RESEARCHER>

Consent statement

I confirm that I have read this form and that the research project and the purpose of my participation in it have been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and I have been promised to receive a copy of this consent form after I sign it.

Participant's name in block letters:	
Participant's signature & date:	
Signature & date of person obtaining consent:	