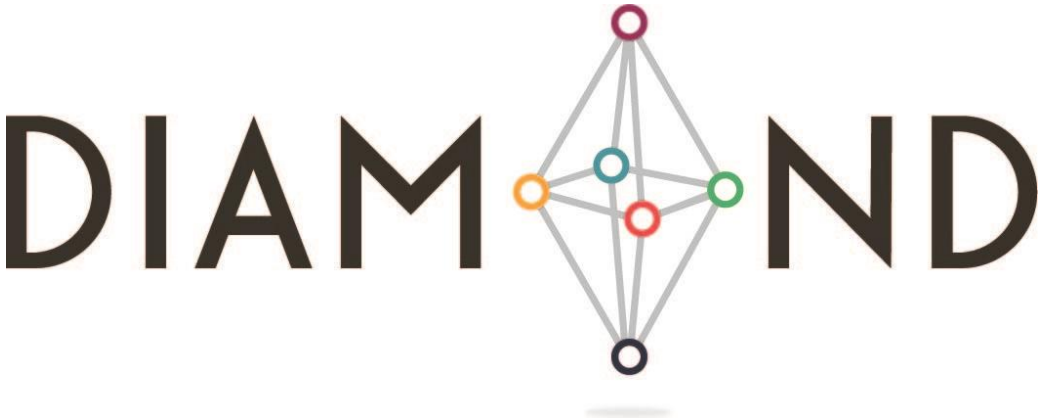

Deliverable 8.2
A Guide to Interview Ethics
DIAMOND project

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Executive Summary

This document (Deliverable D8.2) sets out a *Guide to interview ethics* for the DIAMOND project. It aims to provide partners with a framework for dealing with ethics that must be used when collecting and analysing interview (qualitative) data in the project. The document also acknowledges the Responsible Research and Innovation (RRI) principles, as set out by Horizon 2020, that all DIAMOND partners will follow.

In general, ethical research is built on trust and integrity, including avoiding potential conflicts of interest or causing harm to participants or researchers and ensuring all data collected is handled properly. It helps ensure that participants (such as interviewees) involved in the research are provided with sufficient information to decide on whether or not to take part in the research, and that they explicitly and voluntarily give their consent to take part. All information gathered is considered anonymous and confidential, unless explicit consent is given otherwise. Ethical research also avoids interviewing vulnerable people, unless essential to the research and there are careful safeguards in place to support this.

This document sets out some broad ethical principles for conducting ethical interview research in relation to the collection and analysis of data to the publication and use of the data. International data sharing and secondary data analysis are briefly mentioned although they are set out in the separate Data Management deliverables.

The key ethical concerns which arise with interview and other data collection are also highlighted and discussed in relation to the planning and preparation of data collection, including the collection and use of social media data.

The document concludes with a list of ethical recommendations for the DIAMOND research project and provides an additional list of further reading materials relating to research ethics

Section 1 gives an overview and introduction to the key ethical issues in interview research. Section 2 sets out some key issues of Research integrity that should be followed. Section 3 describes some ethical principles for interview and related research in the DIAMOND project. Section 4 describes the process of what DIAMOND researchers should do in this regard. Sections 5-8 briefly outline Secondary Data Analysis, International Data Sharing, Data Collected via Social Media and finally some general Recommendations for DIAMOND. The Appendices present some indicative examples of Information Sheets and other forms and further details.

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Terminology and Acronyms

EC	*European Commission*
EU	*European Union*
FP	*Framework Programme*
PMB	*Project Management Board*
PMP	*Project Management Plan*
STAB	*Scientific and Technical Advisory Board*
WP	*Work Package*
RRI	*Responsible Research and Innovation*
GDPR	*General Data Protection Regulation*

1. Introduction

This document sets out the main ethical principles for research involving interviews, focus groups and related research in the DIAMOND project. Key benefits of such ethics consideration include protecting participants and others (both directly and by thinking through potential problems in advance) and improving the quality of the research.

Section 1 gives an overview and introduction to the key ethical issues in interview research. Section 2 sets out some key issues of Research integrity that should be followed. Section 3 describes some ethical principles for interview and related research in the DIAMOND project. Section 4 describes the process of what DIAMOND researchers should do in this regard. Sections 5-8 briefly outline Secondary Data Analysis, International Data Sharing, Data Collected via Social Media and finally some general Recommendations for DIAMOND. The Appendices present some indicative examples of Information Sheets and other forms and further details.

Ethical guidelines for social research across Europe are usually based on the joint development of specific rules and norms within different disciplines which have been created in line with research integrity expectations (see below), the European Convention of Human Rights (ECHR) Article 8[1] and current General Data Protection Regulation (GDPR) regulations[2]. Of course all research in the project should follow relevant EU, national and discipline-based ethical and research integrity guidelines.

Employing and carefully following an ethical framework is fundamental to all research projects where human participants are involved (and other research). Ethical principles focus on issues such as anonymity, confidentiality and informed consent. These occur at all phases of the project from deciding the focus of the research, the participants chosen, the methods used to collect data, storage of the data and the dissemination of the findings. By adhering to a clear and uniform framework of behaviours and actions across the research process, the researcher is able to help ensure the integrity and accountability of the project and therefore its findings. Contemporary research ethics are in the main based around the concepts of "…consent, proportionality, necessity and the right to withdraw" with many authors claiming the increased focus on research ethics to be related to the uncovering of many 'unethical' projects[3].

All empirical research (such as interviews) must receive formal ethical approval *BEFORE* being carried out, otherwise the data should not be gathered. The formal ethical approval should be provided by the partner's formal ethical approval body, or if this does not exist, then from the DIAMOND project ethical 'committee' (or other body who gives formal ethical approval). Retrospective approval will not normally be given (in which case the data should not be used in project analysis or results as it was collected unethically).

The DIAMOND project will also follow Horizon 2020's Responsible Research and Innovation (RRI) principles as set out in their 2018-2020 work programme (https://ec.europa.eu/research/innovation-union/pdf/expert-groups/Responsible_Research_and_Innovation.pdf). RRI principles are employed in all H2020 funded projects that involve research with and for "societal actors", offers a "new mental model for innovation policy"[4] and involves multi-disciplinary and international partners working together throughout the whole research process to "…align the processes and outcomes with the values,

needs and expectations of society"[5]. In practice, this means that partners in the DIAMOND project will: ensure that they will engage relevant stakeholders and members of the public in their research; enable access to all outputs via gold or green level open access platforms; include a gender dimension in the project; and conduct research that is ethical and meets local and national data protection and GDPR legislation.

2. Research Integrity

A set of principles that need to be applied to all research carried out as part of the project concerns research integrity. The 'European Code of Conduct for Research Integrity Principles'[6] states the need for research to incorporate:

- **Reliability** in ensuring the quality of research, reflected in the design, the methodology, the analysis and the use of resources.
- **Honesty** in developing, undertaking, reviewing, reporting and communicating research in a transparent, fair, full and unbiased way.
- **Respect** for colleagues, research participants, society, ecosystems, cultural heritage and the environment.
- **Accountability** for the research from idea to publication, for its management and organisation, for training, supervision and mentoring, and for its wider impacts.

Ethical research in the DIAMOND project should meet these standards of integrity.

3. Ethical principles concerning interview research

Ethics is about both *what* you do and *how* you do it. In general, ethical research is built on trust and integrity, including avoiding potential conflicts of interest or causing harm to participants or researchers and ensuring all data collected is handled properly. It helps ensure that participants (such as interviewees) involved in the research are provided with sufficient information to decide on whether or not to take part in the research, and that they explicitly and voluntarily give their consent to take part. All information gathered is considered anonymous and confidential, unless explicit consent is given otherwise. Ethical research also avoids interviewing vulnerable people, unless essential to the research and there are careful safeguards in place. All participants must be treated fairly (see for instance D2.2), including ensuring different groups are not discriminated against or exploited and are fairly represented in the research and not all benefits fall on one group. All participants must be treated with respect, including prioritising participants' welfare, culture, beliefs etc. before the research objectives.

Specifically, EU requirements suggest that in work packages, where interaction with external actors will take place (for example where surveys, interviews, focus groups and panel discussions are involved), informed consent and data protection measures are required[7]. When collecting primary data, sufficient information must be provided to participants and informed consent procedures followed, including signing a confidentiality agreement where applicable. These will be in language and terms understandable to the participants. (Where secondary data sources are used, then equivalent consent should have been given by participants to those who gathered the

original data).

The external participants to the research (e.g. interviewees) will have the right:

- To know that participation is voluntary (with no direct or indirect pressure being put on them to participate);
- To ask questions and receive understandable answers before making a decision;
- To know the degree of risk and burden involved in participation;
- To know who will benefit from their participation (e.g. who funds the research);
- To know how their data will be collected, protected during the project and either destroyed or reused at the end of the research;
- To withdraw themselves and their data from the project at any time (or they are informed of restrictions if their data cannot be withdrawn, say, at some future date);
- To know of any potential commercial exploitation of the research.

Each partner in the DIAMOND project must request from the data controller (see GDPR) of their institution that the necessary measures for the technical data protection procedures have been implemented for the project. These measures will serve to demonstrate compliance of the data protection processes with the European legal framework.

In general, these concerns are based on the concepts of not causing (physical or mental) harm to participants, ensuring participation is totally voluntary, ensuring that participants can give their informed consent to taking part in the research, keeping the responses of participants confidential or anonymous, and avoiding involving vulnerable people unless necessary and full safeguards are in place. These are now briefly discussed:

3.1 Cause no harm to participants (or researchers)

Research that will cause harm (physical, mental, emotional, financial) to participants is regarded as unethical and unacceptable to most researchers (i.e. researchers must follow the principle of non-maleficence). Harm can be defined as physical harm, causing stress to the participant physically or emotionally[8] or distress caused to the participant by taking part in the research. One issue with the concept of causing no harm is that as researchers we cannot always identify all circumstances that may cause harm to participants (e.g. discussing a sensitive issue that may distress the participant such as asking about car accidents from someone who has lost a relative in one). This can partly be avoided by using informed consent (see below), so participants are aware that such potentially sensitive issues will be discussed. Also there should be a contingency plan in case someone gets upset during the interview (e.g. a printed information Sheet with credible organizations that can provide suitable emotional or other support). Ethics requires thought about such issues before interviews are carried out, so that contingencies can be carefully considered.

The safety of the researchers is also an ethical issues, so interviews should only be carried out in safe places/times (e.g. a researcher meeting a participant alone in an isolated area late in the evening is likely to raise safety issues).

3.2 Voluntary participation

The principle of voluntary participation requires that participants are not coerced into participating in any research. This is especially relevant where researchers had previously relied on 'captive audiences' for their subjects - prisons, schools, universities, and such like. It refers to a human research subject's exercise of free will in deciding whether they wish to participate in a research activity or not. International law, national law, and the codes of conduct of a variety of scientific communities protect this right. The level of effort involved in clarifying voluntariness depends on several circumstances, such as the respondents' abilities to resist pressures like financial inducements, authority figures, or other forms of persuasion.

Special care, therefore, must be taken to eliminate undue pressure (real and perceived) when research subjects have a reduced capacity to refuse (e.g. having a manager putting pressure on their staff to participate in interviews). This also includes the right for participants to remove themselves and their data from the project without causing them any negative impact. The information provided to participants should indicate that refusal to participate or a decision to withdraw will not result in any penalties or loss of benefits to which the participant is otherwise entitled. However, it should also be made clear how important the participant is and how much it means that he or she complete the study. In some cases, it will not be possible to remove participant responses at a later date (e.g. because the information has been used or published and cannot be retracted etc.) – in such cases participants should be informed about this before they give consent. Information on participants and how they are selected (including inclusion and exclusion criteria and how potentially vulnerable people's rights are protected), should be specified in the ethics application.

3.3 Informed consent

Participants must give their informed consent which involves them understanding what they are consenting to, not being forced or coerced to participate and having the legal ability to consent (e.g. being old enough or not suffering mental impairment etc.) Participants must understand what the project is about, what their participation involves and any possible dangers (e.g. questions on sensitive topics) before they consent to take part. Normally, an *Information Sheet* (with a hard copy always available for the participant to take away with them) provides this information. The participant is then usually asked to sign a *Consent Form*, which also highlights relevant key issues (see below). In general, all international and national guidelines recommend or require the written documentation of informed consent. Obtaining appropriate informed consent is necessary **before** any interview begins. It is an ethical obligation as well as a legal requirement designed to protect the basic human rights of research participants. It is therefore important to ensure that each participant has understood all the information provided to them. The *Information Sheet* should be clearly written, in an appropriate way for the participant, and include information regarding (see Appendix 1 for an example):

- a brief (perhaps one sentence) description of what the interview/project is investigating;
- who funded it;
- the degree of risk and/or burden involved in participating;
- how long the interview is likely to take;

- that they can withdraw themselves and their data from the project (up to specified time);
- that they can refuse to answer any question without explaining why;
- how their data will be collected and stored during the project and either destroyed or reused at the end of the research;
- who will benefit from participation;
- if there is any potential commercial exploitation of the research;
- If data are to be archived (and used by others in the future) then this must be made clear.

All participants should be provided with time prior to making a decision to participate where they can ask questions and receive understandable answers before making a final decision.

The challenge of informed consent is to provide sufficient information to make an informed decision, while at the same time presenting this information in a way that the potential participant understands and that does not waste too much of their time. The participant's education, maturity, and cultural environment may affect their ability to understand such information therefore care should be taken when developing support documents to ensure they will be suitable for the intended audience.

Having been given sufficient information and the opportunity to ask questions, normally participants will be asked to sign a *Consent Form* (Appendix 2). There is debate on whether each statement in the Consent Form should be initialled, or only one signature of the participant is needed at the end. There are also different practices as to whether the participant should be given the choice of deleting some sections (a danger being that the researcher could delete them afterwards).

The informed consent process can include different types of materials such as the form that people must sign, project fact Sheets that explain the study, and flyers or posters that tell about the study.

- Documents must be in the local language, use local terms, and be written for a language level that potential participants can easily understand.
- Concepts, images, and support materials in general should be appropriate to the local community.
- Translations should be accurate, of high quality, and be verified by back-translations.

It is also advised that materials and forms be piloted (tested) for appropriateness before they are used in screening or actual enrolment. This should be done by someone very similar with the types of individuals to be recruited for the study. Following this, the materials may need to be revised to make them more understandable. The use of support materials, such as brochures or videos, should also be considered. In some cases, researchers may also need to create mechanisms to communicate with others, such as participants' partners, family members, or friends.

3.4 Anonymity/Confidentiality

With qualitative interview data (e.g. interview notes, video or audio recording etc.) particular care should be taken to ensure that there is no possible way of identifying a participant or their location. In the main this is achieved by using pseudonyms (e.g. fictitious first names) for both individuals and locations in published reports. From a social research perspective, confidentiality can be described as the explicit guarantee given to participants by the researcher that the data they collect will be anonymised with all key identifiers removed. Hence no individual should be identifiable from any published reports. By employing a confidential approach to the collection and dissemination of research data, the researcher is able to a) remove any way of identifying

participant's personal identities from their records and b) encourage participants to be more forthright in their answers[9].

Where subjects consent to participate in research, access to personally identifying information and its use should be carefully guarded. Identifiable data should be coded at the earliest possible time. A minimum number of research staff, all of whom must be instructed about confidentiality requirements, should have access to the data. In qualitative research, direct quotations of participants are typically used in the presentation of results. In this case, care must be taken by the researcher to ensure that they do not contain information that may be potentially identifiable. Participants should also be informed that direct quotations will be used, without identifying information.

Confidentiality

Maintaining the confidentiality of information collected from research participants means that only the investigator(s) or individuals of the research team can identify the responses of individual subjects; however, the researchers must make every effort to prevent anyone outside of the project from connecting individual subjects with their responses. Usually the collected information is identified by a code and then a separate, encrypted database links the code to the details of the participant.

Anonymity

Anonymity strictly means that the researcher cannot identify the participant either, although in practice often it is used to mean the same as confidential. Anonymous information collected from research participants means that either the project does not collect identifying information of individual subjects (e.g. name, address, Email address, etc.), or the project cannot link individual responses with participants' identities. A study should not collect identifying information of research participants unless it is essential to the study protocol.

Data Management and Secure Storage Once obtained data should be kept secure from theft, copying, interception and/or casual release. Records should be kept in locked cabinets to which access is restricted to as few members of the research team as is reasonably possible. Similarly, data which are stored on computerized databases should be secure from access by other users of the system. At a minimum electronic data must be password protected and preferably encrypted to preserve security of the data. Participant data (without identifying information) and coding lists (with identifying information) should be stored separately. Files and Memory sticks containing information should be encrypted. Paper copies (e.g. of interview notes) should normally be stored double locked (e.g. a locked cupboard or drawer in a locked room).

3.5 Vulnerable groups

When planning and conducting research, researchers should always consider the additional ethical concerns or issues arising from working with potentially vulnerable participants. Vulnerability can be defined in a variety of different ways and can arise as a result of age, potential marginalisation, disability (e.g. however, simply being old does not make someone vulnerable, it depends on, for instance their health status etc.) and due to disadvantageous power relationships within personal and professional roles. According to the European textbook on ethics research (European

Commission, 2010: 53)[10], vulnerability is a very complex concept and the following indicators could be used to define vulnerable groups:

1. Subjects who lack competence will be unable to protect their interests by choosing to give or withhold consent.
2. If the voluntariness of the subjects' consent is compromised, this may similarly prevent them from choosing to give or withhold consent in a way that would protect their interests.
3. The physical (or psychological) condition of some subjects leaves them especially liable to harm, for example as a result of frailty through age, disability, or illness.

Participants may not be conventionally 'vulnerable', but may be in a dependent relationship that means they can feel coerced or pressured into taking part, so extra care is needed to ensure their participation is truly voluntary[11]. The concept of vulnerability signals mindfulness for researchers and research ethics boards to the possibility that some participants may be at higher risk of harm or wrong[12].

In addition to vulnerable subject groups such as children (under the age of 18) and prisoners, there are special classes of subjects including students, employees, and cognitively impaired individuals who may be vulnerable in terms of their research participation. Subjects are considered vulnerable when they are not respected as autonomous agents and/or their voluntariness is compromised. There are two important types of vulnerability:

(1) Decisional impairment, whereby potential subjects lack the capacity to make autonomous decisions in their own interest, perhaps as a result of undue influence/inducement.

(2) Situational/positional vulnerability, whereby potential participants may be subjected to coercion

Researchers should therefore consider the following:

- Participants' vulnerability
- Potential negative consequences or lack of personal benefits from their involvement in research, where these are expected
- Providing appropriate information to elicit freely-given informed consent for participation as well as information regarding data deposit and data re-use (where data archiving is possible)
- Limits to confidentiality and occasions where this may occur
- Legal requirements of working with the specific population (these may vary by country)
- Incentives and compensation for participation.

However, researchers must always confirm with their individual ethics committees and national legislation before commencing any research with groups or individuals who may be seen as vulnerable. In some countries it may be necessary to get a criminal record check for the researcher before interviewing young people (under 18 years) or other vulnerable people[13].

3.6 Conflicts of interest

All partners must clearly identify to the Ethics Board and to all participants (other partners, interviewees etc.) any potential conflicts of interest. They must take action to avoid where possible any such conflicts and clearly highlight them in all results from the project. Conflicts of interest may include, for example where: partners or staff may benefit financially; results and data conflicts (e.g. care must be taken not to suppress or restrict access to any results etc. that do not support their other work); the research may benefit financially for certain results; the research is

particularly interesting to another organisation where the researcher also works or is an office holder.

4. Putting principles into practice – what needs to be done

Formal ethical approval must be given by an appropriate body (e.g. the Ethics 'Committee' of the organization) BEFORE any empirical research is carried out. Each partner will decide who their appropriate ethical body is. Where there is no local ethical body, the DIAMOND project Ethics Board can consider the application and should normally give a decision (e.g. approved, revisions required, refusal) within one month of a full application being received by the DIAMOND project managers, Eurecat.

The ethics approval should consider issues (and see evidence through, e.g., copies of information Sheets, Consent Forms, questionnaires) such as: of avoiding harm to participants or researchers, voluntary participation, informed consent, confidentiality and anonymity, and vulnerable people.

An example of the process for the ethics approval etc. of the interview research is:

Ethics approval

1. Before applying to the appropriate ethics approval body (e.g. the Ethics Committee of the organization), the research design should meet the principles discussed above. If, for instance, vulnerable people are to be interviewed, then alternatives should be considered and if these are not possible then suitable safeguards put in place.
2. Formal ethical approval must be given before any empirical research is carried out (e.g. interviews held).
3. All research personnel should have received the relevant training to allow them to conduct competent and scientific research without bias and to present their research goals and intentions in an honest and transparent manner.
4. The research should be carried out in full compliance with, and awareness of, local customs, standards, laws and regulations and the ethical approval of the relevant body.

Before the interviews/ focus group etc.

5. It is important that procedures for interviews are set out in writing, and clearly explained to interviewees before each interview starts; this is usually done at the same time as inviting the participants by including a participant information Sheet (see Appendix 1). The information Sheet will also include the contact information for the researcher, their organisation and details of how the collected data will be used. All interviewees should be supplied with the written version of these procedures before they agree to take part in the project.
6. Freely given informed consent should be obtained from all participants (see Appendix 2). Potential participants should be informed, in a manner and in language they can understand, of the context, purpose, nature, methods, procedures, and sponsors of the research. Participants should be fully informed of their right to refuse, and to withdraw themselves and their data from the project, usually up to a reasonable time prior to publication.
7. Research teams should be identified and contactable during and after the research activity.
8. In some projects, participants may also ask to view an interview guide before they agree to take part in the research, in this case it is usual to provide participants with an indicative

interview guide which sets out the broader high level concepts which will be examined in the interview.

9. Details of who will have access to the information collected, how and where the information will be used, the manner in which it will stored and how long it will be stored for should also be set out clearly in the information Sheet provided to participants (see Appendix 1).
10. Each participant should then be given the opportunity to ask any questions they may have before beginning the interview.

During and after the interviews etc.

11. The welfare of participants should have the highest priority; their dignity, privacy and interests should be protected at all times. Confidentiality and anonymity are an important concerns for all social research. The processes to be put in place to safeguard each participant's anonymity and confidentiality through the project should be set out clearly in the informed Consent Form (see Appendix 2).
12. Interviewees should always give their consent in writing and if this is not possible an explanation must be given as to why. If material is to be published or preserved as a public resource, then permission will need to be explicitly given by the participant in writing.
13. If there have been any sensitive issues (e.g. discussing accidents) (or if, extremely rarely and with suitable safeguards, there has been any deliberate lack of clarity during the interviews, e.g. so as not to bias participant responses) then there may be a debriefing of participants and a hardcopy debriefing Sheet given out and explained (Appendix 3).
14. As stated above, participants should be offered a hardcopy of contact details for the researcher and their organization (usually on the Information Sheet). Also they should be asked if they want a summary of the results – and if so their details should be collected (usually on the Consent Form).

Ethical issues affect all stages of the qualitative, interview research process. Before the research actually begins the planning and design phase begins with identifying a research topic and designing the study. The design of the project is based on questions such as the following:

- What research questions will add to understanding of the topic?
- What kinds of data will be required to answer these questions?
- Are interviews the most effective means of examining the research questions?
  What other methods might be used to collect or generate data? (e.g. surveys, observations, documents, examination of naturally-occurring data?)

5. Ethical issues related to secondary data analysis

Ethical considerations should always be taken into account when using pre-existing data, particularly around potential harm to individual subjects and issues of consent[14]. Secondary data (collected by another organization or for another purpose/project) which have been collected for a specific purpose, such as that of social attitude or health surveys, differ in the amount of identifying information which is retained and the consent that participants have given for the use of their information.

Generally four of the questions that each researcher should ask themselves before commencing work on an existing data set[15];

1. How will you navigate the consent process for participants? What did the original Consent Form signed by the participants say regarding further use of the data once collected? Should they be, or can they be, contacted and asked for their consent?
2. Are there any GDPR implications? As above, have the original participants been asked if they were willing for their data to be made available for further research projects?
3. Is there a possibility that the participants will be identifiable or recognisable in any way? People can become identifiable even within large-scale data sets - perhaps because they have distinctive characteristics (e.g. families with large numbers of children may stand out in cohort studies) or because a method of analysis combines variables in ways that identify small groups within a larger sample.
4. What are the responsibilities towards the researchers who collected the original data? Has permission to use the data set been sought and given?

Sharing research data provides researchers the opportunity to answer new research questions in existing data, saving time, money and resources[16].

6. Ethics issues related to international data sharing

Responsible conduct in data sharing requires protections around the issues of discrimination, security standards, and standards of confidentiality and privacy. There should be very good governance and oversight, and the security of the data should be guaranteed. Issues include:

1. The need to manage privacy and confidentiality when data are being shared and datasets can be merged, such that the sharing may generate information that allows people to be identified.
2. Concerns about "moral distance" or whether the uses of data by those a distance away from where they were collected will take into account the expectations of those who first collected and provided the data in a particular context.
3. The possibility of valid consent - and if so, is it really possible to achieve valid consent when the future uses of data are unclear?
4. The need to consider social justice, including stigma and discrimination.
5. The potential impact on public trust and implication for future research. For example, if data are used inappropriately, such as published in ways that are discriminatory, that might have implications for the trust of communities and the public in the scientific enterprise.
6. Issues related to decision-making and who decides who gets access to data and who does not, and what counts as appropriate involvement in the data-sharing and data-access policy process[17].

The Organisation for Economic Co-operation and Development (OECD) Data sharing Mechanisms for the safe and responsible sharing of personal data, including mechanisms for the protection of privacy of data subjects as well as for public input and accountability, should be established and made public by data owners/controllers. Data should be shared as openly as is feasible within the relevant legal and ethical constraints. Of course all EU regulations must be followed. Issues on Data Management will be included in the Project's Data Management Plan.

7. Data collected via social media

The rise in use of social media platforms for socialising and networking has seen them become a focus for much contemporary research on a variety of topics from behaviours to attitudes. Online communities of wide ranging interests can be found across multiple platforms and have become of interest to social researchers in relation to the relative ease of accessing 'user-generated content' that is "typically rich, numerous and naturally occurring"[18].

However, as discussed above, informed consent is a fundamental part of conducting ethically based research and this raises questions as to how data collected from social media can be utilised in an ethical manner. Hence it is important to:

1. Check the terms and condition of the platform being used to collect data (many of which include clauses on the accessing and re-use of data by third parties) - questions of whether social media posts are public or private can be determined to some extent in the terms and conditions of each platform that individuals have signed up to.
2. Ensure informed consent of all participants – related to the above note and whether researchers are ethically bound to seek permissions and consent from individual users.

Together with these ethical concerns surrounding the use of data collected via social media in terms of participants being informed, there is also the issue of the participants of research having the choice to withdraw themselves and their data from any study. Many researchers and research bodies[19] who have collected data from social media platforms have gone on to ask important questions regarding the deletion of posts or accounts for example. Can we, as researchers, assume that the deletion of a post equates to withdrawal, and if so how can researchers ensure that all posts remain live whilst the study is ongoing?

A further key concept underpinning ethically robust research is based on maintaining the anonymity of our research participants, particularly in relation to qualitative research. Traditionally researchers who have collected primary data at source will have assured their participants their anonymity will be protected, with extracts of the data published using pseudonyms or codes. However, if sections of text are being used in publications or presentation verbatim, this could be used to identify the source. Inadvertently breaching social media user's anonymity therefore has the ability to increase the risk of harm to participants resulting in both professional and organisational damage, and perhaps even prosecution[20].

When conducting cross-national data collection partners must ensure that interviews are conducted only by appropriately trained, qualified and experienced researchers, in the native language of the country.

8. Recommendations for DIAMOND's research

1. The points on ethical interview research set out in this document should be followed.
2. Individual partners will decide whether formal ethical approval for their activities is required. If this is required, it will be sought from the relevant institutional ethics body linked to their organization (e.g. the university ethics committee). If there is no such body, then they should consult the DIAMOND Ethics Group for formal agreement before proceeding.

3. All partners involved in primary qualitative data collection will ensure that interviews are conducted only by appropriately trained, qualified and experienced researchers.
4. All participants taking part in DIAMOND's research should be given sufficient information to provide informed consent and normally be asked to give signed consent. Participation should be entirely voluntary.
5. All participants will be notified about the retention period of their data, the purposes for which their data will be used, their right to withdraw their participation and their data at any time and that their participation is entirely voluntary.
6. Participants in DIAMOND's research should have access to the findings from this work, such as research publications or briefing papers. These will be made available, subject to any copyright restrictions, on the project webpage.
7. When collecting social media data for inclusion in the DIAMOND project, researchers should firstly consult the terms and conditions of the platform under study, including information for third parties being given access to data from the platform, and ensure they meet the principles set out in this paper.
8. All research data collected for DIAMOND should be held in an anonymised format (with information linking individual names or identifiers held in a separate secure file).
9. The individual partner who collects the primary data will retain the key for breaking anonymity securely, and will not release this to other partners unless absolutely necessary.
10. All partners in the DIAMOND project have a responsibility to ensure that their data collection and storage systems are highly secure and follow all GDPR regulations. Data will be stored only on password-protected computers/laptops and preferably encrypted.
11. Should 'cloud storage' systems be used, then the data protection requirements are followed by the cloud storage host must meet EU standards.
    When sending encrypted data from one partner nation to another, only very highly secure systems should be used.

All partners will, whenever requested, confirm that they have followed full ethical procedures and have full ethical approval from a relevant body. This will also form the basis of a report to the European Commission each year. The DIAMOND project Ethics Board will:

1. Receive, approve or require proposals from partners whose own institutions have no relevant ethical procedures;
2. Draw up and ensure that all team members engaged in research with human subjects sign an undertaking form which binds them to the projects' ethical procedures as set out in the current document;
3. Respond to ethical questions and issues arising in the course of the project.

For Further Reading on EU research ethics see appendix 4.

DIAMOND

DIAMOND

Appendix 1. Participant Information Sheet – Example [to be amended as appropriate]

Invitation
You are being invited to consider taking part in the following research study.

DIAMOND Project Participant Information Sheet

DIAMOND - Revealing fair and actionable knowledge from data to support women's inclusion in Transport systems.

Purpose of the project:
DIAMOND is a research project to help identify and test how to make the current transport system fairer to all, and particularly for women. [or specify the part of the system as appropriate] It is funded by the European Union[1] and involves 14 partners from 10 EU countries including academics, transport operators and planners, public authorities and experts in infrastructure assessment design. The knowledge gathered in the data analysis will then be fed into a toolbox that will provide recommendations.

Why have you been invited to take part?
You have been invited to take part in your capacity as a member of a transport organisation/employer in the transport sector/employee in the transport sector/user of public transport.

What does participation involve?

1. You are being asked to take part in an interview and/or focus group which should last approximately 1.5 hours. You will be asked questions regarding the concept of fairness in transport use and employment for women, the barriers to fairness and requirements needed to improve fairness.
2. The interview will take place at a place and time convenient to yourself and your line manager.
3. You will also be asked to sign a permission form to allow the interview to be recorded. The recording will be used to make a more accurate transcription of the discussions taking place. The recordings will not be made available to anyone outside of the DIAMOND project and will be deleted within 6 months of the project finishing.

[1] H2020-MG-2018-SingleStage-INEA N° 824326

4. Findings from the interviews will be passed to project partners in an anonymous form. Individual transcripts will only be shared with project partners if a question arises about an entry in the aggregate table.
5. All information gathered will be treated as anonymous and confidential. No data will be revealed which could identify any respondent or group taking part in this project.
6. You are free to decide whether you wish to take part or not: your participation is entirely voluntary. Deciding not to take part in this project will carry no penalties. If you do decide to take part you will be asked to sign two Consent Forms, one is for you to keep and the other is for our records.
7. You can decline to answer any particular questions without giving a reason why.
8. If you change your mind during the study you are free to withdraw yourself and your data up until ……..
9. All information gathered will used to complete the project and any possible associated academic papers.
10. Potential commercial exploitation – the results of this interview may be used in the development of potential commercial products such as ….. [***This part only applies where relevant, otherwise delete it***].
11. Do you have any questions?

If you have any concerns about this study or if you are interested in obtaining the research results, please contact me at cc@ABC.com or

If you have concerns or other queries, you can contact Dr Joan Smith, Director of Research Ethics at Joan Smith University at JS@js.edu or tel. +44 xxx xxx.

Appendix 2. Consent Form – Example to be amended

PARTICIPANT CONSENT FORM

DIAMOND - Revealing fair and actionable knowledge from data to support women's inclusion in Transport systems.

Please answer the following questions by ticking the response that applies

	YES	*NO*
1. I have read the information Sheet for this study and have had details of the study explained to me.	☐	☐
2. Any questions I had about the study have been answered to my satisfaction and I understand that I may ask further questions at any point.	☐	☐
3. I understand that I am free to withdraw from the study at any time without giving a reason for my withdrawal or to decline to answer any particular questions in the study without any consequences to my future treatment by the researcher.	☐	☐
4. I agree to provide information to the researchers under the conditions of confidentiality set out in the information Sheet.	☐	☐
5. I wish to participate in the study under the conditions set out in the information Sheet.	☐	☐
6. I consent to an audio recording being made of this interview.	☐	☐
7. I consent to the information collected for the purposes of this research study, once anonymised (so that I cannot be identified), to be used for any other research purposes related to the DIAMOND project (e.g. academic publications).	☐	☐

Participant's Signature: _____ Date: ___/_____

Participant's Name (Printed): _____

Contact details:

Researcher's Name (Printed)
Researcher's Signature: _____

Appendix 3. Debrief Sheet - example

Debriefing Form for Participation in a Research Study XXX from XXX Organisation

Thank you for your participation in our study!

Your participation is really appreciated.

Purpose of the Study:
We previously informed you that the purpose of the study was [insert brief sentence about purpose of study]. The goal of our research is to [insert statement(s) describing any research hypotheses and the results/findings you were/are looking for].

The next stage of this research is to analyse these results and attempt to create a picture of……and any associated challenges.

I am of course happy to answer any additional questions you may have. I can do this just now or else my contact details are included in the information Sheet.

Confidentiality:
You may decide that you do not want your data used in this research. If you would like your data removed from the study and permanently deleted please [insert instructions on how participant can have study data deleted].

Final Report:

If you would like to receive a copy of the final report of this study (or a summary of the findings) when it is completed, please feel free to contact us.

Useful Contact Information:
If you have any questions concerning your rights as a research subject, you may contact……

Further Reading(s):
Provide two references (text, article, on-line reference, etc.) that can be easily accessed by the targeted population in this study.

Appendix 4. Research Ethics Principles

Horizon 2020 Research Ethics[21]

All the research and innovation activities carried out under Horizon 2020 shall comply with ethical principles and relevant national, European Union and international legislation, including the Charter of Fundamental Rights of the European Union and the European Convention on Human Rights and its Supplementary Protocols. Researchers working on H2020 projects are encouraged to pay particular attention to the principles of proportionality, privacy, the protection of personal data, the integrity of the person, non-discrimination and the need to ensure high levels of human health protection.

Research participants' rights are fundamental anchored in human rights and the ethical principles that govern all scientific research.

Horizon 2020 Regulation 1291/2013 Ethical Principles (Article 19)[22]

- Honesty- present their research goals and intentions in an honest and transparent manner;
- Reliability- design their research carefully and conduct it in a reliable fashion, taking its impact on society into account;
- Objectivity- use techniques and methodologies (including for data collection and management) that are appropriate for the field(s) concerned.
- Impartiality- ensure objectivity, accuracy and impartiality when disseminating the results;
- Open communication- participating in open access obligations as much as possible and taking into account the legitimate interest of the beneficiaries access to research data, in order to enable research to be reproduced
- Duty of care- exercise due care for the subjects of research be they human beings, animals, the environment or cultural objects;
- Fairness and responsibility for future science generations- refrain from practicing any form of plagiarism, data falsification or fabrication.

The European Code of Conduct for Research Integrity Principles (2017)[23]

- Reliability in ensuring the quality of research, reflected in the design, the methodology, the analysis and the use of resources.
- Honesty in developing, undertaking, reviewing, reporting and communicating research in a transparent, fair, full and unbiased way.
- Respect for colleagues, research participants, society, ecosystems, cultural heritage and the environment.
- Objectivity requires facts capable of proof, and transparency in the handling of data.
- Researchers should be independent and impartial
- Accountability for the research from idea to publication, for its management and organisation, for training, supervision and mentoring, and for its wider impacts.

European Social Research Council Framework for Research Ethics[24]

- Research participants should take part voluntarily, free from any coercion or undue influence, and their rights, dignity and (when possible) autonomy should be respected and appropriately protected.
- Research should be worthwhile and provide value that outweighs any risk or harm. Researchers should aim to maximise the benefit of the research and minimise potential risk of harm to participants and researchers. All potential risk and harm should be mitigated by robust precautions. (Should u/g dissertation involve vulnerable participants?)
- Research staff and participants should be given appropriate information about the purpose, methods and intended uses of the research, what their participation in the research entails and what risks and benefits, if any, are involved.
- Individual research participant and group preferences regarding anonymity should be respected and participant requirements concerning the confidential nature of information and personal data should be respected.
- Research should be designed, reviewed and undertaken to ensure recognised standards of integrity are met, and quality and transparency are assured.
- The independence of research should be clear, and any conflicts of interest or partiality should be explicit.

Further Reading

Horizon 2020 the EU Framework Programme for Research and Innovation page 266 Ethics and Research Integrity
http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/amga/h2020-amga_en.pdf

Stakeholders Acting Together on the Ethical Impact Assessment of Research and Innovation (SATORI Project) SATORI: Stakeholders Acting Together on the Ethical Impact of Research and Innovation http://ethics.iit.edu/eelibrary/node/17904

Ethical Assessment of Research and Innovation: A Comparative Analysis of Practices and Institutions in the EU and selected other countries (SATORI Project)
https://cordis.europa.eu/project/rcn/111019/brief/en

EU H2020 Commission Ethics in Social Science and Humanities October 2018
http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/h2020_ethics-soc-science-humanities_en.pdf

A report on the legal frameworks that guide or constrain ethical procedures within research within the EU March 2015 http://satoriproject.eu/media/SATORI-Deliverable-3.1-.pdf

OECD Research Ethics and New Forms of Data for Social and Economic Research

https://www.oecd-ilibrary.org/science-and-technology/research-ethics-and-new-forms-of-data-for-social-and-economic-research_5jln7vnpxs32-en

Ethical Protocols and Standards for Research in Social Sciences Today June 2015 Science Europe Scientific Committee for the Social Sciences https://www.scienceeurope.org/wp-content/uploads/2015/09/20150911_Workshop-Report_Social_Ethics_web.pdf

ENDNOTES

[1] ECHR Article 8 states that all individuals have the right to privacy in family and family life and that this right is to be protected at all times. In compliance with these EU rights, contemporary research ethics therefore partly focus on issues and concerns around the concepts of '…consent, proportionality, necessity and the right to withdraw' European Commission (2013) p.3 Ethics for Researchers; facilitating Research Excellence in FP7 accessed at http://ec.europa.eu/research/participants/data/ref/fp7/89888/ethics-for-researchers_en.pdf September 2015
Horizon 2020 Programme, https://ec.europa.eu/programmes/horizon2020/en/h2020-section/ethics
[2] GDPR includes how data are collected, processed and stored and is based on the principles of lawfulness, fairness and transparency; purpose limitation; data minimisation; accuracy; storage limitation; integrity and confidentiality (security); and accountability. For example see: Information Commissioner's Office https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/principles/. The DIAMOND project also has a data management plan which includes these issues.
[3] European Commission (2013) *op cit.*
[4] Owen, R (2012) Responsible Research and Innovation: Options for Research and Innovation Policy in the EU
[5] EU Research and Innovation Participant Portal
[6] http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/h2020-ethics_code-of-conduct_en.pdf

[7] http://ec.europa.eu/justice/policies/privacy/docs/wpdocs/others/2006-07-03- vademecum.doc

[8] Bryman, A. (2015) Social Research Methods, 5th ed., Oxford University Press, Oxford
[9] Bryman, A. (2015) *op cit.*
[10] http://ec.europa.eu/research/participants/data/ref/fp7/89867/social-sciences-humanities_en.pdf.
[11] Research with potentially Vulnerable people Economic and Social Research Council https://esrc.ukri.org/funding/guidance-for-applicants/research-ethics/frequently-raised-topics/research-with-potentially-vulnerable-people/
[12] Roche, D., Bell, E., MacDonald, M.E and Racine, E. (2017) The Concept of Vulnerability in Research Ethics

[13] For example the Protecting Vulnerable Groups (PVG) Scheme in Scotland, which covers all EU nationals https://www.mygov.scot/pvg-scheme/

[14] The Research Ethics Guidebook a resource for Social Scientists at http://www.ethicsguidebook.ac.uk/Secondary-analysis-106
[15] Tripathy, J. (2013) *Secondary Data Analysis Ethical Issues and Challenges* at https://www.researchgate.net/publication/278044529_Secondary_Data_Analysis_Ethical_Issues_and_Challenges

[16] Townsend, L. and Wallace, C. (2016) Social media Research: A Guide to Ethics, University of Aberdeen https://www.gla.ac.uk/media/media_487729_en.pdf

[17] Sharing Research Data to Improve Public Health in Africa: A workshop Summary: Committee on Population; Division of Behavioural and Social Sciences and Education; The National Academies of Sciences, Engineering, and Medicine Washington (DC): National Academies Press (US); 2015 Sep 18. https://www.ncbi.nlm.nih.gov/books/NBK321546/
[18] Nat Cen 2014 Research using Social Media: Users' Views.
[19] British Psychological Association (2013) Ethics Guidelines for Internet---Mediated Research. Townsend and Wallace (2016) op cit.
[20] Townsend, L. and Wallace, C. (2016) *op cit.*
[21] Horizon 2020 Research and Innovation Ethics http://ec.europa.eu/research/participants/docs/h2020-funding-guide/cross-cutting-issues/ethics_en.htm
[22] REGULATION (EU) No 1291/2013 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 11 December 2013 https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2013:347:0104:0173:EN:PDF
[23] The European Code of Conduct for Research Integrity http://www.allea.org/wp-content/uploads/2017/04/ALLEA-European-Code-of-Conduct-for-Research-Integrity-2017.pdf
[24] ESRC Framework for research ethics https://esrc.ukri.org/files/funding/guidance-for-applicants/esrc-framework-for-research-ethics-2015/