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PROMoting ethics and integrity in non-medical REsearch

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EXECUTIVE SUMMARY

The thematic priorities report has been compiled based on the individual, concluding reports of the ten workshops which were organised within WP2 of the PRO-RES project, and, more particularly, as defined in Task 2.2 “Thematic focus groups creation and first series of workshops”. The topics covered by the workshops are as follows:

- Research Funding Organisations and Ethics (EPC);
- Technological innovation (cutting edge research like nano, biotech etc.) (NTUA);
- Privacy, surveillance and covert research (K&I);
- Ethics in the context of intelligent Decision Support, Autonomous Systems, Social Media and Bioinformatics, *in short Data Science* (UT);
- Research ethics in disaster and conflict settings (DCU);
- Ethical Frameworks and Responsible Research - Challenges to Science in a Changing World (K&I);
- Ethics in finance and economics research (EPC);
- Ethics, Social Mining, and Explainable artificial intelligence (CNR-ISTI);
- Ethics in Policy Advice (economics and finance research) (EPC);
- Ethics, Integrity and Qualitative Research Methods (AcSS).

The **workshops involved different types of stakeholders** (related project representatives, science/technology experts, regulators, funders/research councils and policymakers) across various non-medical scientific fields. Their aim was to find common spaces where relationships can be improved or, in some cases created, in a cycle of research shared with policy cycles, and in developing better mutual understanding of different professional bases.

During the workshops, the participants had the opportunity to **present their experiences regarding existing support of ethical research** in their own fields. The list included guidelines on research integrity (Science Europe); a code of good behaviour (European Federation of Academies of Sciences and Humanities); compliance with a Concordat on research integrity to access funding (UK Research and Innovation); a code of conduct signed in 1991, with a voluntary scheme for adhesions -though in fact you can't refuse it (Finnish National Board on Research Integrity); a code to stop ethics dumping, which is now a mandatory document for Horizon 2020 funding (TRUST Project); among other relevant experiences.

Following the existing experiences, an outcome of the workshops included the conclusions of the participants' discussions regarding ethical and RI issues that emerge within specific scientific fields, and suggestions on the ways and format that the PRO-RES framework will ideally deal with them. This should enable all involved stakeholders to face successfully the ethical and RI challenges in their fields of expertise.

The **main issues discussed in the workshops** focused on 4 areas, which were the basis for further recommendations: awareness raising, training, the implementation of systemic approaches, and the need to base policy on ethically robust evidence. These issues were touched across diverse fields of research (topics covered in the workshops as previously mentioned) and brought as the centre of debate the following questions:

- Regarding the privacy of research, the main question posed was about the independence of the researcher with respect to the funding body and from issues related to the involvement of community in research activities. In a society of enhanced “surveillance”, how to manage informed consent and the use of data? What would be the impact for disadvantaged groups? Similar problems occur when doing observational research in public areas.

- In terms of Data Science and Social Media, the questions pointed to understanding the ownership of the data, how to publish critical results and how data could be perceived differentially based on cultural backgrounds and uses.
- For the issue of ethics in disaster and conflict settings the ethical discussions focused on the integrity of the researchers, the imminent saturation of the researched community (overwhelmed by many researchers coming to the areas), the process of involvement of local communities as well as the high uncertainty and instability of the research site - which may require greater flexibility on ethics protocols and sensitivity to the setting.
- Regarding Responsible Research, the issue of technological innovation was at the centre, including topics such as the credibility of and trust in science and social institutions, the increasing need for accountability, how to deal with the fragmentation of science and the issue of increasing interdisciplinary research and how to develop better ways of evaluating research beyond quantitative output measures.
- Another topic discussed was finance and economics research, having as main issues the management of big data, the biases derived from the fact that researchers are paid to do research to achieve certain outcomes (ideological and research by request bias), among others.
- Artificial Intelligence and Social Mining were also a focus of discussion as it is becoming a disruptive technology, mostly dominated by giant tech companies. Indeed, the monetization of the research process was a sensitive topic raised during the workshops.
- Regarding Policy Advice, the main topics covered were: how can research be truly independent? How to develop an effective code of conduct and how to sanction/punish those who do not follow the code? Could there be any realistic penalties for the unforeseen consequences of new technologies, discoveries, etc.? Additionally, some social, political and economic issues were pointed as ways of influencing the policy making process such as social movements, the terminology on sustainability and the circular economy, transparency (e.g. disclosing negative evidence), among others.
- Last, the questions of integrity, ethics and qualitative research raised a deep discussion including a variety of topics about research in general and the various qualitative methodologies (conventional ethnography, arts-based research, digital data, data analysis, etc.). The issues discussed included informed consent, the understanding of visual elements, emotional impact, the management of digital data from access, publishing, the boundaries of public/private space, confidentiality, intellectual property, the secondary uses of data, language use and the contextual factors for interpreting/making sense of data, etc.

Based on the workshop discussions, the participant stakeholders proposed and recommended a **number of solutions and the ways the PRO-RES framework may incorporate them**. The key solutions emerging are:

- Develop an approach that works as guidance; that is positive (emphasizing the good things); that complies with guidance at a national level; is user-friendly, accounting for the whole research system; and, that provides a navigable route through the complexity.
- Promote the use of right data for policy making and target policymakers and further stakeholders (industries, third sector, etc.) to deliver a science-based transformative change.
- Suggest penalties to overcome obstacles, which are applicable for all people involved (e.g. authors, reviewers, editors).
- Introduce values that can be culture-specific, respecting the differences between the disciplines and that deals with the variety of high standards produced in different fields.

- Promote the notion of responsibility as a realigning factor to broaden the scope of ethics and integrity of science (swift from compliance to responsibility focus).
- Ensure the flexibility and permeability of the framework, avoiding a “box-ticking” approach.
- Change on the way science and research is evaluated and revise institutional structures for research performance evaluations.
- Highlight the role of young researchers as transformative agents for the future of science, increasing the training on ethical issues and by raising awareness about it.

Along with these key solutions, research in the future might bring further issues that should be also considered in the framework. Topics such as research in international contexts, technology assessments, the role of open science and vulnerability in research were discussed.

Last, it was agreed there is no need to develop further specific guidelines as there is already an extensive amount of them available, covering diverse fields of research, yet not grouped in an efficient way. Therefore, the goal should be to aggregate and ***provide a coherent and user-friendly framework*** that includes the suggestions emerging from the project, that is accessible for all researchers, policymakers and general public. The development of the framework might be aligned with a strategy of incentivisation to use such guidelines, with a focus on the involvement of young researchers.

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1. Introduction

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- Ethics in Policy Advice (economics and finance research) (EPC);
- Ethics, Integrity and Qualitative Methods (AcSS).

The report is structured following a set of questions (the ‘thematics’) that framed the discussions within the workshops. It concludes with five annexes containing a list of participants, types of participants per workshop and in total, the geographical distribution of participants, and gender balance.

One of the first issues to come up in the workshops was the difference between ethics and integrity and whether ethics and integrity should be managed together. While people often think they understand the concept of ‘integrity’, ‘ethics’ issues tend to be more blurred. This can lead to a tendency to steer clear of them, although the concept of integrity is sometimes also vague about whether it relates to a research project or to the researcher carrying it out. ‘Integrity’ is often associated with negative cases, “when things go wrong”, and linked to misconduct and sanctions. Ethics issues are more about the balance between harms and benefits and the choices researchers might have to make.

Respect for Integrity is considered to be an organisational responsibility. This is where codes of best practice may have an impact. If a researcher (of any level) does not show respect for research integrity, he/she does harm to science in general, and their academic discipline in particular. In Western Europe, breaches are now mostly handled by Commissions on Research Integrity within each institution. Such bodies do not always exist in Central or Southern Europe. Sometimes a national (oversight or second advice) body exists. However, research integrity issues are too often left to individual researchers, forgetting about organisational responsibility – researchers need both positive support and incentives to pay attention to research integrity.

Ethics in research is considered to be something broader than research integrity. There is no model for the ‘best’, most ethical research. If researchers do not respect research ethics, they may harm people, the environment, non-human animals and, even, the future. Ethical clearance (or approval or an opinion) should be sought in advance of conducting a study. In that respect, the experience of coming from Commissions for Medical Ethics, which are much more standardized throughout Europe, can be helpful.

As far as the PRO-RES project is concerned, the distinction between ethics and integrity is acknowledged, although both will be considered.

On various occasions within the workshops, it was highlighted how the application of standard ethical review procedures, not originally designed for certain disciplinary fields, can produce paradoxes that jeopardise the pursuit of those same ethical aims. For this reason, one of the main objectives of PRO-RES should be to maintain the balance between promoting general principles applicable to all types of research and across different disciplines, while maintaining those elements that recognise the specific identity of each discipline. The ethical framework of PRO-RES should influence policy/regulators across disciplines, professions and sectors and help promoting research ethics and integrity in Horizon Europe. PRO-RES should be concerned with the proper relationship between research and public policies; the social value of independent research; and the promotion of trust in research among both policy makers and the wider public. As part of this reflection a number of problems have been reported:

- Difficulty for researchers to orient themselves with respect to the variety of different codes, guidelines and existing frameworks;
- Difficulty for researchers to orient themselves with respect to the existence of rules, ethical review systems and different institutions;
- Certain orientations of the current institutional infrastructure of research organisations (such as the pressing drive to publication in high impact factor journals) can induce researchers to make mistakes or forfeit their integrity;
- Treating medical ethics rules as necessary and sufficient for regulating research activity in any other disciplinary field;
- Poor reflection and awareness among researchers of the motivations, interests and stakes, involved in their research activity, including its wider ethical implications for the common good;
- Poor awareness among researchers of the importance of ethical issues, which are sometimes ignored, sometimes considered just as an onerous bureaucratic obligation;
- Heterogeneous research methodologies and practices characterising different scientific areas raise a wide range of new ethical issues and problems;
- Innovations that challenge the existing consolidated ethical systems;
- Problems in ensuring the safety of researchers and participants;
- Bad communication on ethics in research, especially regarding on-line communications;
- Presence of stereotypes among operators and institutional committees/ethics committees that influence research (for example, differentiated decisions with regard to men and women in protecting the researcher's safety; prejudices about specific geographical areas or disadvantaged groups);
- An excess of rules and prescriptions, which if applied too literally, obstruct research activities;
- National regulations tend to differ and, at times, can be mutually inconsistent even among EU member states;
- Even within the same country there are very different attitudes by disciplinary associations towards research ethics, ranging from the non-recognition of the issue to very detailed codes;
- Institutional diversity in review and evaluation systems;
- Excessively strict or inappropriate procedures discouraging research in difficult areas or making important social and humanities research virtually impossible;
- The need to bring some balance between freedom of science and ethical principles. Researchers typically, also, have roles in addition to conducting responsible research, e.g. sitting on advisory boards, where they also need to be aware of the ethics issues.

The role of ethics committees and the problems associated with them are, also, considered as relevant. In particular, the following have been indicated:

- Difficulties related to the relationship between ethics committees and researchers, in defining their role (obstructing the researcher or acting as a guide or advisor) and in the long timeframes of their assessments;
- Difficulty in distinguishing the different roles of committees involved in the institutional governance of research and in the review of research ethics;
- The creep of reputation management into ethics assessment: protecting the reputation of the organisation prevailing over the freedom of research and societal interests in generating the knowledge (risk averse vs. risk awareness approaches);
- Problems related to the lack of multidisciplinary skills (for example with regard to research methodologies);
- The occurrence of biases in the evaluators that influence the outcome of peer review and evaluation;
- Malpractice and academic in-fights in ethics committees which affect the fairness of the results;
- The need to consider the contribution of organisational contexts to misbehaviour of scientists: some institutional infrastructures can induce malpractice rather than discourage it;
- The need to think about alternative arrangements for the entire appraisal process so that ethics review can fundamentally question methodology or fundamental science (in the event of research being ethically flawed because the methodology is flawed) ;
- The possibility for early appraisal of projects that appear to be inherently unethical;
- Ethics reviews and advisors should act not so much as controllers than as facilitators, supporting the researchers in making their own informed ethical choices;
- Ethics committees should focus more on process than on principles and content (i.e., guiding the researchers to be aware of and understand the ethical implications of their work and take responsibility in addressing them);
- Ethics committees need to take a more holistic approach rather than only focusing on issues that fit the existing boxes, as well as to establish a dialogue, a conversation, to bring ethical difficulties into the light, rather than using protocols that bury those ethical difficulties. Members of ethics committees need to have in-depth knowledge of what conditions can be like in the field, in order to be able to assess research projects that include field research. It should, also, be noted that the ethics committees of operational organisations are different from academic ethics committees.

As already mentioned, any discussion about a new framework should take into consideration the existing ethics guidelines and codes in the various fields of science (e.g. software engineering and computer science). In fact, as already presented, there are several problems that need to be considered when creating a proposed framework. For example: already existing diverse codes, guidelines and frameworks; interdisciplinary differences; varying regulations; various review systems; institutional infrastructures that do not support good practice of research; innovations that challenge existing ethics; and new entrants to the field raising 'old' problems. An ethical framework should be comprehensive and based on agreed values, principles and standards. Agreement is also needed by all stakeholders in constructing and applying the framework. Full dissemination of the framework is necessary – to include training and CPD. The framework should be regularly updated due to social change and innovations in technologies and research methods. PRO-RES, so far, has already accomplished the following elements for achieving the framework: stakeholders list and mapping existing codes and guidelines matrix, illustrative case studies, workshops (on various non-medical fields), glossary of terms and concepts, framework draft, website, statement of ethical principles for research, and newsletter.

2. What works to support ethical research in your field?

During the workshops, the participants had the opportunity to present their experiences regarding the existing support of ethical research in their own research field:

- **Science Europe** working group on integrity have produced guidelines on how research funding organisations (RFOs) can collaborate. It focuses on research integrity, narrowly defined as the absence of research misconduct – or the absence of FFP (falsification, fabrication, plagiarism). This working group has produced guidance especially around collaboration between different funding contexts. ALLEA (the European Federation of Academies of Sciences and Humanities) have produced a code of good behaviour, emphasizing that most researchers are honest members of the research community. It also describes what should not be considered good behaviour, describes principles behind research integrity, and why good behaviour is a *sine qua non* for the development of science.
- **UK Research and Innovation (UKRI)** was established to increase permeability between disciplines. Compliance with its Concordat on research integrity is a condition of funding for institutions. However, poor levels of compliance have been found, as well as a lack of transparency around issues of misconduct. UKRI is investing in doctorate training, looking to see where improvements can be made. It also works with the Royal Statistical Society to boost the statistical competencies of researchers to avoid questionable practices.
- **National Science Centre in Poland (NCN):** The situation regarding ethics and integrity in Poland is not very systematised. There are very high levels of mistrust within the country, and low levels of trust in the state. There is no ethics committee in the National Science Centre. There is only a committee looking at scientific misconduct. There is no systematic way to identify ethical issues. Coordinators and reviewers flag up issues that need to be considered. Ethical questions remain within panels drawn from the scientific community (for example, if human subjects are used in an engineering study, it is engineers that will decide if it is ethical). People do not really think about the ethics part of the proposal, just fill in the requirements of the funder. Scientists do not view the ethics forms as important, although this view is changing slowly.
- **TENK** is the Finnish National Board on Research Integrity – founded in 1991, first code of conduct in 1994 – one of the first Boards of this kind in Europe. It is independent of universities. Commitment to guidelines is technically voluntary but in fact you cannot refuse it. The first national guidelines on ethical principles of research in the humanities and social and behavioural sciences were published in 2009; revision is due next year driven by GDPR. They have a responsible research website – it took two years to create, needs one full-time person to maintain, fulfils some of the objectives that PRO-RES aspires to. Responsible research website, small articles available for public and researchers. All guidelines and recommendations are there. To keep it running, it needs funding all year round. They have trained 130 trainers. The challenge now is to bridge the gap between new PhD students, who are very familiar with the guidelines, and older professors, who are not.
- **Committee on Publication Ethics (COPE):** Its overarching aim is about culture, changing norms rather than imposing regulation from the outside. Implementation and adoption is the key. It is a charity with volunteers from very diverse backgrounds, staff in the UK but also a very international organisation. It was started in the biomedical sciences and is now 20 years old. It has been working to diversify its membership and influence on other fields. The number of ethics cases seen annually in journals is fairly consistent across different fields.

- An example of bad publication practice in one university led to an internal guideline to be voted on which was then owned by the persons who voted for it. The guidelines worked, because of the engagement of the researchers with the decision process. This gave them a sense of ownership of the guidelines, in contrast to the common problems with top-down approaches. There is, also, some scepticism about having a framework that has to be followed.
- **TRUST Project:** The major aim of this EC-funded three-year mission-driven project was to stop ethics dumping, and it was concluded in December 2018. Ethics dumping refers to researchers exploiting differences in regulations between countries such that researchers from higher-income countries do research in lower-income countries which would not be permitted in their home country. The project collected cases which are available on the project's website. An ethics code has, also, been created to prevent ethics dumping, based on the values of honesty, care, respect and fairness which were found to be held around the world. This code is written in simple language, contains just 23 articles, and is now the mandatory document for Horizon 2020 funding.

3. Issues identified per area of expertise regarding evidence-based policy making.

One participant claimed that in their ethics appraisal process, 60-70% of proposals which have ethical issues come from the social sciences and humanities. It is not clear why, but it may be because there is less support from local/regional/national organisations to researchers in these fields which contrasts with the Life Sciences. Additionally, there is a lot of research being conducted outside Europe, and in some of these countries there are no review bodies or relevant regulatory authorities. Finally, the use of methodologies that are typical of Life Sciences, but without the usual structure that Life Science scientists have when dealing with human subjects, may create relevant implications .

The main areas in which discussion has been focused are:

Awareness-raising

There is need to invest in raising awareness about integrity and ethics issues. This does not necessarily mean taking costly actions. It may simply mean having policies that are publicly accessible; including relevant information in funding calls, ideally in English, and providing a contact person who can advise on issues related to ethics or integrity. The issues should be flagged up on application forms and reflected in the contracts. It has been acknowledged that mandates to change behaviours do work and create leverage.

Training

As a minimum, funders should require that everyone involved in a research project have received some training on good research practice. Research Funding Organisations should also ask that people involved should have received a basic training on ethics (non-optional). Regarding the question about who trains the trainers, and who bears the financial cost for that, this is perhaps an area for European funding.

Examples of a Systemic Approach:

UKRI: In the eyes of the public, who fund research, all research is tarnished by one big case of misconduct. Systems approach is, also, important, not just tinkering with one thing; hence a whole stakeholder approach is needed.

ALLEA:

- Independent ethics advisers;
- Self-regulation works if it is practiced as intended;
- Protection for whistle-blowers and sufficient internal mechanisms through which they can voice their concern;
- Fostering trust within the system to facilitate the implementation of regulations;
- Transparent principles and guidelines can help. For instance, having clear guidelines for when an ethical review is needed is important;
- Research integrity monitoring at project level;
- Need for more research into the impact of the incentives researchers face.

TENK: In the Finnish context, this is necessary if a research project fulfils at least one of six criteria:

- intervention in the physical integrity of subjects;
- deviation from the principle of informed consent;
- subjects are under 15 years;
- subjects are exposed to exceptionally strong stimuli;
- study may cause mental harm;
- study may pose security risk.

ERC: There is need for a social contract between funders and researchers to establish responsibilities. Individuals need to be empowered with responsibilities, but the largest burden of responsibility needs to remain with institutions (so they can foster the appropriate cultures).

Basing Policy on Evidence:

Flemish commission for research integrity: Evidence based policy is about rightfully applying research results to (public) policy. It is a shared responsibility between researchers, communication departments of research institutions, science journalists, policy makers (ministers, CEO's, civil servants), think tanks, academies/learned societies and other organisations issuing reports with scientific policy advice and recommendations. In this context, it is acknowledged that the path from lab to law can go horribly wrong. While researchers have some responsibility (for instance, not to tweet misleading things), the process mostly goes wrong with non-researchers (like policymakers).

3.1. Privacy, surveillance and covert research

The main ethical problems in **privacy research** start from the freedom of research and the independence of the researcher, from the relationship between researchers and public or private funding bodies, and from issues related to citizen involvement in research activities. The main ethical issues in studies of surveillance have to do with informed consent and use of data in the so-called 'surveillance society'. There are also issues relating to restrictions that may be imposed on some areas of social research by excessive or inappropriate ethical regulation. The conditions under which covert research can be conducted, together with the relationship between public and private spheres and some problematic elements in research ethics, are all part of this discussion.

Regarding privacy, the first main issue is the definition of research on privacy as looking to “understanding the enjoyment of the right of private life, family life, home and communication”. The effects of the new General Data Protection Regulation (GDPR) on the world of research are significant: increasing awareness among researchers about the importance of protecting personal data, but, also, creating the sense among researchers that such protection might increase their bureaucratic burdens. Convention 108, “Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data”¹, which has been signed by a considerable number of countries, should also be considered as a measure for the protection of privacy. Regarding GDPR, there has been particular reference to art.5(1b), regarding the centrality of the purpose for which personal data are collected: “[data] collected for specified, explicit and legitimate purposes [shall not be] further processed in a manner that is incompatible with those purposes; further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes shall, in accordance with Article 89(1), not be considered to be incompatible with the initial purposes (‘purpose limitation’)”. In fact, it is accepted that most research activities are made possible mainly as “derogations” from this principle (see article 89 of GDPR).

The participants in the relevant workshop identified the following general problems:

- Researchers’ awareness of the intended and unintended effects of research on the privacy of participants;
- Researchers’ problems in limiting the collection of data to what is indispensable for their research;
- Problems in guaranteeing anonymity and confidentiality;
- Problems in managing the ownership of the collected data and their use. One suggestion was to promote an ethical review specifically on the use of information and personal data.
- Problems in the management of collected data (embargo and censorship requests);
- Problems in ensuring the independence and freedom of the research team with respect to both public funding bodies (including Law Enforcement Agencies and Intelligence Services) and private donors (such as Over the Top companies in the digital sector);
- Problems related to the relationship with the funders about the risks of exclusion and the tendency towards the precarious employment of researchers even with respect to the processes of changes that affect the scientific and technological research system;
- Problems in the relationships with some funding bodies on the publishing of results (request for secrecy of results or embargo);
- Difficulty in accessing funding for research on certain topics or using certain methodologies;
- Excessive pressure from some officers in charge of evaluating the progress of research projects, including European ones, to change the contents of reports;
- Difficulties in determining needs and defining the parameters of involvement with large private companies in the digital sector (Google, Amazon, Facebook, Apple, etc.);
- The tendency to turn personal data into a commodity.

Regarding **surveillance studies**, the following general problems have been identified:

- The collection, management and processing of data and big data;

¹ See <https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/108>.

- Social sorting - categorising people as objects of surveillance activity based on stereotypical criteria, with the risk of causing damage to the people involved;
- Surveillance creep, or the possibility of using surveillance activities - carried out for a certain purpose- for a different purpose, namely extending and combining data harvesting;
- Data slippage, namely moving from one context to another – retrospectively asking questions that initially had not even been conceived;
- Risks related to the dual use/misuse of the data collected;
- Informed consent: many surveillance activities are hidden and data processing is invisible; traditional methods of collecting consent are thus problematic or unfeasible;
- Pervasiveness of surveillance activities may create in people a sense of powerlessness and resignation or discouragement;
- Lack of transparency in the algorithms used in the management, data storage and construction of data sets and data analytics, also based on belief in their alleged objectivity. Big data contain unexplained values and principles that can harm people;
- Broad implications when digital big data are used to make decisions that have an impact on individuals (bail decisions, predictive policing, etc.);
- Unreliability of data anonymisation and pseudonymisation procedures;
- Ethical problems in the use of biometric and digital surveillance technologies and in automated smart systems;
- Risks of social exclusion and higher penalties for disadvantaged groups;
- Social media post tracking activities to identify political opponents;
- Risks of exclusion/discrimination in the case of smart systems, using automated decision making, linked to the basic algorithms used.

Regarding **covert research**, the specific workshop thought that this mode of research is often misunderstood in current literature in ways that may exaggerate its ethical problems. One common misunderstanding equates it to deceptive research. In contrast to deception, where the aims of the research are initially misrepresented or not fully disclosed, and participants debriefed at its conclusion, covert research is simply a research activity, which is not disclosed for various reasons. Examples of covert research include observational research in public areas (like a stadium or a post office), where the request for informed consent would be simply impossible and meaningless; research in which, for good methodological reasons, one wants to have a naturalistic appraisal of interactions that would be altered if the researcher were to disclose their identity from the beginning; and research in areas where disclosure could imperil the researcher and/or the participants.

The general problems identified in relation to covert research are:

- The tendency to confuse covert research with research using deception;
- Consent is not always informed, meaning that the participant is not always able to evaluate all the implications connected to his/her involvement in the research. It is therefore necessary to consider how consent is obtained and constructed: mere consent is often not sufficient to protect the private sphere;
- Different research methods require different levels of consent;

- The current rules make it difficult to involve vulnerable groups in research activities; such groups thus risk being doubly excluded even from studies that could represent an opportunity to express their point of view and their experiences;
- Uncertainty in calibrating the level of disclosure of information about the research to be provided to the participants;
- Inappropriate procedures to ensure confidentiality and anonymity. Problems exist with ethics committees that have often refused authorization for research that involved the use of covert methods.

3.2. Ethics in the context of intelligent Decision Support, Autonomous Systems, Social Media and Bioinformatics (*Data Science*)

In the field of Data Science the main problems arising are:

- Social sciences and the ‘buy the results’ button;
- The question of how to use open source data (the unknowns are inconsistent with quality, different practices of acquiring and presenting the data);
- Challenge of anonymity in genomic research, because it is not possible. There is, also, a question of informed consent in big biobanks: broad consent is needed because of the likelihood of newly emerging research questions. Dynamic consent could be a solution for that. Complicated consent forms are necessary due to legal obligations;
- Question of publishing critical results (e.g., air quality in buildings). Who is responsible for consequences of publishing the research results, who should publish, who owns the results, is there something such as independent research?
- Importance of privacy and its legal perspective: what is private, what is semi-/public space, especially in social media?
- Question of defining and categorising research. Sometimes the research purpose is unclear. Different disciplines have different standards (and possibly different ethical requirements);
- Issue of cultural differences in ethical perception;
- Question of the role of the researcher and transparency for the research participants. When do we say it is ok not to disclose your role as a researcher? Trust as a key aspect of the scientific community;
- Ownership of the data. Who owns the data?
- Issue of objectivity and bias in research – is it necessary to keep the distinction between the roles (private and research role)?
- Issue of the role and necessity for approval of the ethics committees for the research. Going ahead without ethics approval is common in software engineering, for instance. In addition, it is not legally required. There are some advantages of not regulating the process of ethics in research too much. Outsourcing the ethics responsibility to the ethics board is a risk but it is often a common practice. There is, also, a risk of creating a “Nanny-Society” which is overregulated with too many rules, codes etc. to follow;
- Ethical questions should be part of training programmes;
- Random ethics approvals/audits might help – high penalty and probability of being caught needs to be high;
- Peer review processes as the core academic mechanism could be a chance for also reviewing ethical issues but it is not today;
- If ethics help to improve the study this might be very helpful;
- Ethics by design, e.g. in proposal templates of the EC;

- Ethics “approval” is not a yes and no outcome but should be a process which helps to refine ethical considerations. There are advantages of the AGILE/scrum approach for ethics review.

3.3. Research ethics in disaster and conflict settings

Regarding research ethics in disaster and conflict settings, the relevant workshop’s participants reported on their research experiences within disaster and conflict settings:

- In the case of a study about the training and supervision of researchers – in particular, principal investigators (PIs), research supervisors, and research assistants (RAs) – working in three post-conflict countries in south Asia, it was reported that training, particularly for RAs, tended to be systematic, didactic and repetitive, whether classroom-based or online. Role plays were sometimes added to classroom-based training to assist with practical application. There was no clear process or format for supervising field researchers, and unethical practices were identified in the field. The emphasis was on ethics as static, standardised and auditable, rather than as a way of balancing principles to reach a judgement in a given context.
- The International Committee of the Red Cross (ICRC) has a new research centre and their aim is to set up an ethics review process for ICRC research. ICRC face various macro ethical issues as well as the micro problems. For example, it is impossible to be independent and impartial in highly politicized contexts where people are suffering. As an operational organisation carrying out research, in a couple of worst case scenarios, the lives of staff involved could be at risk if they act in ways that communities do not like, or ICRC could be expelled from a country if their research findings are not what the government wants to hear. Additionally, working with participants can be difficult because of cultural politeness or people’s expectations of ICRC, either or both of which can lead them to tell you what they think you want to hear. Moreover gatekeepers may not always act in the best interests of their community which can affect research processes and outputs.
- A lot of research is done in the military, in times of peace and conflict and in humanitarian crises. Research is not generally part of missions where the military are called in because civilian resources are exhausted. The military have a lot of resources but can be quite insular, lacks civilian oversight, and doesn’t always appreciate criticism from outside. Also, the military itself can be viewed as a vulnerable population of potential research participants because hierarchical and authoritarian relationships, and/or peer pressure, within the military can affect the status of consent. It was, also, reported –in the workshop-, that the American military prefer ‘special population’ or ‘captive population’ to ‘vulnerable population’, and has mandated protections in place to alleviate concerns around coercion.
- There was particular reference to the case of Lebanon, where public health research has been conducted, as well as teaching in a context of conflict and forced migration. Around 1 in 4 people in Lebanon is a refugee. Global research collaborations are compromising ethics. Refugee communities are becoming saturated with researchers. There is a growing literature around this but it is a problem yet to be solved.
- Regarding journalism and experiences in relief work in disaster and conflict areas, it was reported that there are tensions between the ethical need to do research in disaster and conflict areas, and the people in those areas who are in great need of help which participating in research is unlikely to provide. Journalists are now doing more social science-type research, using data science skills and resources to gather good evidence to support their reports. Journalistic ethics seem to be moving closer to research ethics. Journalists are concerned about whether people feel compelled to co-operate rather than freely giving consent; whether they are putting people’s lives at risk; whether they are retraumatising people. At this point, the work done by the Dart

Center for Journalism & Trauma (a project of the Columbia University Graduate School of Journalism) is relevant. On the other hand, it is acknowledged that it is very important to get information out to the world. That information can influence policy, unleash charitable giving, and become part of the historical record.

- Researchers from Médecins sans Frontières (MSF) work with populations for years, providing huge advantages for conducting research with those populations but, also, disadvantages in the form of bias. MSF researchers are working in complex environments and respect for human rights and international law is a foundational requirement for ethical research. The MSF ethics board, unlike some, while also being a regulatory requirement, is a valuable resource offering dialogue with people who can offer an independent neutral perspective, on any ethical issue, not only those concerned with research. It is not always clear whether what MSF are doing is research, because another part of their work is témoignage i.e. speaking out on what they see when the people they are helping cannot do that, e.g. to bring atrocities to the public view. There is an increasing link between this and research because both aim to gather and use evidence to effect change. Témoignage is often insufficient on its own, because it can be seen as biased, but combining it with published academic research gives much more weight when advocating for change.
- It is important to involve local communities in the research ethics process and ensure it is iterative and locally relevant. It is, also, very important to ensuring the physical and emotional safety of researchers. To that direction a network focusing on research ethics in disaster and conflict settings would be very helpful. Nevertheless, it is necessary to amplify and include the voices of affected countries, communities, and individuals in these kinds of discussions, respecting the ‘nothing about us without us’ slogan used by some marginalised groups.
- When researchers conduct research in the field, they form a clearer view on what is really happening in a certain environment/context, and they are unavoidably involved personally .
- For humanitarian organisations the ethics space is contested, there is no clear distinction between research ethics and humanitarian ethics.
- There is a huge gap between academics and the field. Research is academic; many of the people who write academic research have never seen what is happening in the field. We need to tackle this gap.
- While we can’t know everything about every context we work with, it is essential to talk about the context when talking about research ethics rather than aspiring to an island of excellence. NATO staff say ‘lessons learned are lessons forgotten’ because context is so important. The context of disaster and conflict zones always includes high levels of instability and uncertainty, and so requires flexibility beyond the control of an ethical protocol.
- Some people think we are in a post-humanitarian period: humanitarianism was once celebrated and championed because it served a certain function in the global order, but that depended on triumphalism. This is now being contested and challenged and is rapidly eroding. When humanitarianism encroaches on the global North, instead of being celebrated it’s condemned. Working in refugee camps in Africa is fine but not rescuing migrants off the coast of Europe.
- A huge amount of money is used on bureaucratic evaluations, often carried out by external consultants, and internal monitoring/evaluation – this money should be used in the field rather than contributing to a graveyard of lost recommendations.
- Operational organisations in the field, and academia, are concerned about publicising their ethical challenges, because sometimes they have to manage them in ‘creative’ ways that don’t fit with funders’ guidelines;

- The staff of organisations that have other staff in the field need to know how to support them effectively. For example, finance staff needs to know how to transfer money to a particular bank in a specific country so that a researcher in the field does not have to make extra journeys in a conflict zone. Furthermore, researchers in the field need psycho-social support, someone to talk to, not necessarily also in the field, can be by phone or equivalent;
- Data protection is a huge issue in disaster and conflict settings. It is hard to translate data protection policies and procedures to the field; hard to control data in uncertain environments and with different cultural understandings. Some institutions are insufficiently aware of these difficulties and their potential implications. Yet failure to protect data can cost lives.

3.4. Ethical Frameworks and Responsible Research - Challenges to Science in a Changing World

Regarding the implementation of the RRI approach in various scientific fields, the following problems were identified:

- The very application of standard ethics review procedures not originally designed for certain disciplinary fields can produce paradoxes that result in jeopardising the pursuit of those same ethical aims;
- The profound changes affecting science as a social institution reflect changes occurring in contemporary societies. These are causing science to modify its structure, mission, rules and organisational features. Such changes seem to be the harbinger of a time where the foundations of science are re-examined, including the incorporation of a new or reinforced concern for ethics. New ethical problems must be confronted as a result of technological and scientific innovation;
- Decreased authority of social institutions including science and some distrust of the scientists as experts (also perceived as having different agendas from the public). This calls into question the integrity of scientists. Their credibility must be re-established in a context where fake science and pseudoscience finds a vast audience;
- Increased demand for accountability of research processes and products;
- Continued trust in the social and economic benefits of scientific research and its capacity to solve problems (request for technical fixes to social and political problems);
- Increased tendency to the political steering of scientific research;
- The de-standardisation and fragmentation of science;
- The tendency to see science as a multi-actor process with a wide range of diverse players, from scientists to the public at large;
- The “sustainability” of RRI as a concept, highlighting the fact that there exist many, sometimes contrasting, formulations and conceptualisation, so that, to some authors, RRI appears more as a proactive drive or slogan, than an analytical notion;
- The possibility that, in the future, RRI might be less central at least in terms of semantics (other expressions like “open science” being preferred), while preserving or even increasing the centrality of responsibility and integrity as the core, the driving force of science policies;
- The boundaries between science ethics per se and the broader concerns brought in by the notion of responsibility, such as public engagement or societal impacts of research;
- The blurring of boundaries between research for academic purposes and for higher impact on society (like from NGOs), which poses new issues of regulation;
- Being responsible should not be taken to mean obedience to a utilitarian approach, but include broader interests in terms of knowledge;
- Especially for new, original, directions of research it could be difficult to specify benefits;
- Evaluating research from quantifiable outputs only can result in undermining the drive to pure research;

- Not all research value can be “monetized” - ethics should be kept separate from issues of commercial advantage;
- Reaffirm the notion that scientific inquiry is a fundamental human capacity and a human necessity.

3.5. Finance and economics research

The main focus is on research involving vulnerable groups (e.g immigrants). In this type of research the main problems that emerge are those of confidentiality which researchers are no longer able to guarantee due to the implementation of strict policies (checking participants’ passports and immigration status). For this reason, one common question is whether researchers are obliged to follow the law, with no exceptions, or whether they should not be obliged to follow unjust laws.

Academic vs. professional researchers, and big data

A distinction should be made between academic and professional researchers. In economics and finance, much research is carried out by associations, private companies, think tanks and other entities. The question is whether the same restrictions apply to them. There is, also, the risk of displacement activity, where researchers move to certain institutions based on what they can do there. Moreover, big data will have a large impact on research and could help with replicability.

There is a lot of unconscious bias: taking big data at face value is risky, as we might attempt to measure things that are intrinsically hard to measure. Additionally, with deep learning techniques it is no longer necessary to have access to the whole dataset, as a sample suffices. However, the underlying assumptions are never neutral, so results can differ widely based on the initial selection of the data. Finally, it is important to establish a common framework for research, especially if the same topic is researched by people from different disciplines.

Giving advice

A potential problem in diffusing common standards and best practice is that scientists are usually not trained in giving advice. In some cases clear rules or criteria are missing, for example on conflicts of interest which could arise if researchers are also paid by large companies. For this reason advisors need to be trained.

Biases, and think tanks vs. academics

Different stakeholders might have different underlying questions, which can lead to misunderstandings and hamper communication even if everyone is behaving ethically.

The issue of algorithmic bias is not new. Indeed, it used to be called model specification bias. It is a systematic problem because individual economists often believe that they are not biased and that their models are accurate representations of reality even when they contradict the models of their peers. Appealing to researchers individually has not worked in the past, and is unlikely to work in the future.

However, it could be argued that this discussion does not apply to think tanks. There is no peer review system (instead, the review of ideas and research is carried out in the public sphere), they are typically not very dependent on academic funding bodies, and their objective is not necessarily truth but impact. As a consequence, it could be argued that while the situation may be unfortunate for academic researchers, think tanks can do whatever they want. However, this view would exclude a large body of research in economics and finance.

When dealing with think tanks, it should be kept in mind that they are in the market for ideas on a daily basis. This is a strong test of the relevance and usefulness of their work and more effective than any ‘box-ticking’ exercise.

More broadly, there are two issues related to level playing field considerations in finance and economics research: a level playing field between different research institutions (i.e. academic institutions and others, such as think tanks and private companies), and one between those that play by the rules and those that do not. Voluntary approaches may not be enough to ensure a level playing field and regulation may be required. Additionally, in other professions, unethical behaviour can lead to the loss of one’s accreditation. This should be an option in finance and economics research too.

Until very recently there was no code of conduct for economists, and ethics issues are therefore frequently questions of trust and ideology. This can lead to various problems, including multiple involvements/conflicts of interest of researchers and biased use of data, which may explain the crisis of trust towards economists. Nevertheless, there are several measures that can mitigate the problem: learning to recognise conflicts of interest through training, favouring an impact-based approach to models rather than a mathematical elegance-based approach, and favouring a global code of conduct for all researchers. For this reason, literacy and communication are important issues.

Furthermore, it needs to be recognised that there are other ideologies and ways of looking at problems, which need to be brought in to find solutions. However, balance is not necessarily a silver bullet. For instance, in the debate before the Brexit referendum, the BBC had to balance every anti-Brexit fact with pro-Brexit claims. Until recently it was similar for climate change. It needs to be made obvious to people what the evidence is, so ultimately it is about transparency more than balance.

You cannot really follow a ‘do not harm’ maxim. Any policy experimentation has a potential for harm. There are always trade-off considerations - doing harm to one group to benefit another or to achieve other policy objectives. There is also a normative/political element. Some people might think that austerity is wrong but advocating it is a normative, legitimate judgement. There can be intentional bias/ideology, e.g. trade union research institutes push a certain angle on the world. In the nature of economics, there are always conflicts of interest. Transparency about interests, coupled with normative codes of conduct/commitment and quality marks, may be the best way forward in those areas where it is not appropriate to ban certain positions by means of legislation.

3.6. Ethics, Social Mining, and Explainable Artificial Intelligence

Big data analytics and social mining raise a number of ethical issues, especially as companies begin monetizing their data externally for purposes different from those for which the data were initially collected. The scale and ease with which analytics can be conducted today completely change the ethical framework. We can now do things that were impossible a few years ago, and existing ethical and legal frameworks cannot prescribe what we should do. Artificial Intelligence is becoming a disruptive technology, and resources for innovation are currently dominated by giant tech companies. To ensure European independence and leadership, we must invest wisely by bundling, connecting, and opening our AI resources having in mind ethical priorities such as transparency and fairness. Within this perspective the following problems emerge when using various relevant applications (e.g. Facebook and other online social network environments):

- The complexity of complaint procedures often discourage users from complaining;

- Laws and ethics are culturally dependent, which means that the same ‘problematic’ content can be treated differently depending on the cultural origin of the user. For example, content including nudity, violence, harassment, fake news, hate speech, terrorism, etc. is treated differently by users coming from different countries and cultural environments;
- The balance between anonymity and responsibility for reporting anything. A clear drawback in removing anonymity is a possible limitation of freedom of speech and can be too over-blocking. The trade-off between accountability and freedoms of expression and information must be considered (in some countries, anonymity is fundamental to protect users);
- The flow of complaints analysis (number of users reporting the same content, number of complaints, clear violation of specific laws, etc.);
- The role of bots;
- Content replication;
- The construction of the database of complaints (how the data are maintained and for how long).

3.7. Policy Advice

In this workshop there was good coverage in terms of a range of expertise and seniority in the attendees and topics across the fields of finance and economics to include issues of equity, ecology and sustainability. Even though the workshop was titled to be about economics and finance – the issues raised were generic to policy advice and it was found impossible to limit the discussion to economics since the issues overlap several disciplines. There was a sense that we need different levels of insight to confront the complex nature of the problems we are trying to address. The argument was that we are confronting a period of discontinuous change which sets a range of challenges. All the examples demonstrate the importance of seeing the issues ‘in context’ – what are the specific details of the case?

The main issues discussed were the following:

Independent research

‘Independence’ is a complex concept and rarely found. How can research ever be ‘independent’ – what is meant by ‘independent research’? Isn’t research always ‘dependent’ – on funding, commissioning, the researchers’ interests and so on? How can independence and integrity be demonstrated in the advocacy agencies. (See ‘transparency’ below.)

Codes of conduct

Can any code of ethical research practice be regulatory – shouldn’t it always be ‘aspirational’ – that is, how can you sanction those who do not follow the code? How can a balance between an aspirational and regulatory system be achieved? There is an argument for a global code of conduct, but one which is also deemed appropriate for the policy-research and advice sector. The success of ethical guidelines will depend on the incentives to use them.

Challenge to the existing models of research

Perhaps conventional methods of gathering research are no longer appropriate. The decision-stakes are so high now that the earlier notion of scientific findings as steadily incremental allowing us to steadily manage problematic outcomes no longer applies. The role of academics changed after the earlier classical economists that had influenced social policy fundamentally changed. It became more a question of how

you marketise society. Collective change processes were being replaced by individualist processes. Instead of a society of citizens the pressure was to create a society of consumers.

A significant modern body of opinion – system uncertainties, decision stakes, post-normal science (cf Ravetz) suggests that even ethically-produced evidence is not the best way to produce policy – a suggestion which might undermine the fundamental premise of the PRO-RES project. Good research is easy to be done – moving on radically is impossible. Big leaps require enormous structural risk. So, conventional research does not deliver radical enough research. We may be locked-in to conventional ways of doing things and need to consider alternatives. **Post-normal science (PNS)** represents a novel approach for the use of science on issues where "facts [are] uncertain, values in dispute, stakes high and decisions urgent". In more recent work PNS is described as "the stage where we are today, where all the comfortable assumptions about science, its production and its use, are in question".

Systems-thinking and systems practice is vital to how PRO-RES moves forward. See for example: the good regulator theorem: [https://en.wikipedia.org/wiki/W. Ross Ashby](https://en.wikipedia.org/wiki/W._Ross_Ashby). The theorem is general enough to apply to all regulating and self-regulating or homeostatic systems, but it does not explain what it takes for the system to become a good regulator. The problem of creating good regulators is addressed by the ethical regulator theorem and the theory of practopoiesis. (See Appendix)

The Commission believes public research money is more comprehensive than it really is. Public money often has strings attached to it which think tanks might not be able to work with. Others spoke of the nightmare of working with the Commission – the language is mystifying and obstructive to ordinary members of the community; connecting with civil society means getting around that obscurantist language.

Ethics principles

The key ethical principle of 'first do no harm' is vital to how this is approached. Although doing no harm is a prime research ethics principle, it is hard to achieve that. Doing harm is inevitable since economics in particular requires making choices and therefore brings up opportunity costs which means someone or some group will necessarily be affected and therefore possibly 'harmed'. Policy experiments rarely produce definitive 'truths'. Even the outcomes of policy experiments might be interpreted differently. Ethical risk and/or impact assessment - is difficult to foresee the consequences of new technologies. Could there be any realistic penalties for the unforeseen consequences of new technologies, discoveries etc.?

Bias

What about ethical bias? Being ethical is still a 'bias' – the bias is towards certain values – the desire to be ethical. How do we (PRO-RES) deal with being moved beyond the requirements of the Commission 'deliverables' – the need to meet the DoA – as a consequence of seeing how difficult these aims actually are? How to deal with funders who 'require' particular outcomes? (Even the Commission has a 'required' outcome for PRO-RES – regardless of what is 'discovered' by the Project.) There is even a difficulty of innovating within the project due to the need to meet the elements of the GA. Maybe even the Commission needs to think in a different way. The Commission does not understand how the 'think-tank' policy-influencing sector works. Many of the agencies do not think the ethics codes and guidelines either apply to them or are relevant to the kind of work they do. Could journalists/journalism offer some light? But journalists can be similarly influenced by writing for news outlets in order to push a particular

economic or political line. All organizations have a 'point of view' and therefore have a bias. Given that bias is inevitable, perhaps it is less of an issue than the benefit of transparency.

Transparency

The importance of transparency – willingness to disclose even negative evidence – i.e. evidence that challenges fundamental 'beliefs' or ideologies. In economics 'schools of thought' frame how evidence or research outputs are interpreted. Even if policy outcomes are chosen it is important to indicate the bases on which those choices were made. Even poor research should be allowed to be made public – the most ethical way of dealing with that is to challenge it publicly. There remains a question of how to deal with the potential for CoI from the funding sources? Perhaps there is nothing wrong with declared interests (e.g. USA openly declares such interests), the question should be how to make them more 'accountable' by agencies with alternative views challenging them. Importance of what is contained in the contractual arrangement – but then how to apply transgressions, think tanks cannot easily take their funders to court on the basis of a contractual agreement – not only will they lose the relationship with that funder and there will also be a reputational effect that undermines their financial survival. So there is a need to bring 'truthfulness' to the table – it may not be possible to prop-up the current system. The only option is to bring about effective change. The ethics that needs to be incorporated – accountability and inclusiveness are the key elements of that policy change.

Influencing policy

How to turn 'movements' (e.g. Greta Thunberg, Extinction Rebellion, Occupy Wall Street) into actual policy? The think tank etc. sector is more influential than the academic sector when it comes to policymaking. But the size of the sector is unknown and the possibility of controlling it is limited. Opaque financing – many think tanks are 'cover' organizations. Think tanks are sometimes set up to push a certain commercial and/or political interest. Difficult to track and regulate it – need to define the sector. Includes NGOs such as Oxfam or MSF etc. Also NGOs commission research. It is a fluid, complex field hard to define and almost impossible to find the key. Between the world wars there was full employment, since the emphasis on growth and GDP has handed over control to 'casino economics' – chasing destructive policies. Refers to elements of the early New Deal began with an ethics framework that did not see the work on nature, the environment, as externalities.

Sustainability – Economic and ecological

Instead of 'de-growth' we need to be talking about 'circular' economies – or better a 'stable state' in which the less advantaged can still feel they are making progress with their lives. Sustainable ecosystems need to be managed at the level of governmental financial departments. (There was talk of the role of groups such as Extinction Rebellion as driving the agenda.) And with the problem of climate change: physics is in the driving seat – politics and economics have to follow. Climate change means that economics and finance have to be re-written. Globally we are unprepared for climate shock. The current prediction is for zero economic growth in 10 years and widening disparity in wealth and opportunities. So there is a need to 'mandate' carbon offsetting: in health services, in education, in transport. There is not enough ethics impact assessment – evaluation of the potential outcomes to research.

3.8. Ethics, Integrity and Qualitative Research Methods

3.8.1. Conventional Data Collection and Arts-Based Research

In this subgroup discussion there was a combined coverage of conventional ethnography (participant observation, interviews, etc.) and arts-based methods including the contributions made to qualitative research by the visual arts, creative writing, performative arts, textile arts, fashion, photography and film.

Conventional Ethnography

In this subgroup of this workshop, the list of possible topics was discussed as aspects of a problem of trust in individuals relative to trust in institutions.

Historically, much qualitative research has been carried out on a highly individual basis, where ethical behaviour has rested on the personal integrity of the researcher and on the promises that they make to research participants about confidentiality and anonymity in exchange for the privacy breaches inherent in fieldwork. This tradition goes back at least to the 1830s/1840s and the work of Harriet Martineau. More recently US researchers have defied court orders and been imprisoned in defence of this principle. Professional bodies, especially in anthropology, have regularly denounced the abuse of this model by security agents of government as a cover story for intelligence work.

However, breaches of trust in other areas and the rise of ethics regulation have led to a reframing of the moral contract with research participants as one that is with institutions rather than researchers. This means that data, for example, becomes corporate property, although its generation depends upon the individual relationships established in the field. Once it becomes corporate property, the researcher cannot honour the conventional guarantees. A good example is the recent Boston College case, where a university was initially reluctant to defend the guarantees of lifetime privacy given to former activists in the Northern Ireland Troubles who were interviewed for an oral history project. For instance, one of the participants mentioned that he/she has deposited his/her own child protection data with the Wellcome Library and closed it for 100 years on the expectation that Wellcome would understand patient confidentiality and defend it more vigorously than any public university.

The discussion covered the following questions:

1. How do we work ethically with gatekeepers?
2. What consent is needed beyond the consent form, e.g. as a process in longitudinal research or in research with cognitively impaired participants?
3. How is consent negotiated and recorded, particularly when writing is not an option?
4. How should we handle unexpected participant distress?
5. How should we manage our own wellbeing as researchers?
6. When should we name participants?
7. When should we pay or otherwise reward participants?
8. What are the ethical aspects of rapport and friendship between researchers and participants?
9. How can we deal ethically with the “non-consenting others” (Mannay 2016) who participants bring into the research context?

10. What are the ethical aspects of doing interviews and focus groups online?

Arts-based research

Regarding arts-based research, the following points refer to why ethics matters in this type of research, why caution is needed and what can be achieved with these approaches.

Photographic images and their dissemination have been a key area of interest in academic practice as once research data are placed in the public domain their impact and interpretation become extremely difficult to control. They are fraught with tensions around revealing and concealing participants identities (and those who are connected to them); and ethical debates about how these images are consumed, shared, and interpreted by different audiences.

But creative methods are not restricted to the realms of photography and film and it is important to explore the affordances, limitations and ethical issues that arise with a far wider range of techniques such as collage, drawing, fuzzy felts, object work and sandboxing.

When we ask participants to become involved in creative activities this process of creating produces an affective encounter. Introducing a visual element to the process of data production can potentially provide different ways of knowing and understanding. This process asks participants to slow down their perception, to linger and to notice, to reflect on their lives and represent them for the researcher, a process that engenders reflexivity and defamiliarization.

Creative practice can overcome the confines of more conventional question-and-answer techniques, open up experience and make the familiar strange for participants. Participants set the agenda through the artefact they create (albeit frequently in response to a research theme or question), they also often lead the conversation around their creation, which can quieten the researcher voice, and enable more spaces of reflection and listening that broaden the associated conversations.

This brings an element of uncertainty to the research process as by providing a gateway to new destinations, the participant, and indeed the researcher, may be confronted with information that was not envisaged at the outset of the project. This can be challenging as what surfaces in these accounts can be unexpected and unintended.

In terms of informed consent, the open nature of creating a visual representation may take the participant, and the researcher, on a different pathway than that set out in the original project brief. The associated institutional and regulatory structures ask researchers to obtain informed consent in the early stages of a research, which mistakenly implies that researchers can know in advance all the purposes data will be put to, and the nature of all the data that is produced.

There are also wider questions about the purpose of research, and the ethical obligations that researchers hold in relation to disseminating their findings. Research studies often generate the standard outputs of chapters and journal articles but their audience is restricted to academia. Arts-based creative mediums of dissemination are increasingly utilised by researchers, who have an ethical imperative to audience their work beyond the confines of academia, connecting with diverse publics to increase understandings and negotiate social change.

The discussion covered the following questions:

1. How can we assess the quality of arts-based research?

2. How can we ensure full methodological disclosure when we report arts-based research?
3. What should we do when it is difficult or impossible to anonymise participants and non-consenting others in arts-based research?
4. What are the ethical implications of participants' levels of arts skills?
5. What are the ethical implications of researchers' levels of arts skills?
6. How can we handle the emotional impact of arts-based work, particularly when it is deliberately intended to provoke, arouse or cause distress?
7. How can we maintain the integrity of images?
8. How do we ethically represent participants in arts-based research?

Based on the aforementioned set of questions related both to conventional ethnography and arts-based research, the main discussion points were the following:

Informed consent

The workshop started out with a thought-provoking point: consent is nearly always uninformed. Unless participants have been through the university system, they don't really know what a conference or a journal is. Unless you've been in a conference you don't know how you'll be talked about. However, consent originates in, and is mostly associated with, the health and medical context. This sets a high bar for explaining risks and alternatives. One attendee questioned whether it is necessary in qualitative research to spell out the possible downsides of participation, particularly as it may deter participation.

Another responded that s/he always informs participants of risks and downsides. Besides fulfilling informed consent, this means participants are "more likely to say yes because they feel like they've been talked to". However, there is a risk to spelling out a finite list of downsides, as you can't spell out everything that may go wrong. Where do you draw the line? A similar concern was illustrated by the "tea trolley problem": someone who shows up unexpectedly (such as a staff member serving tea) may generate data but not be informed of research.

Another attendee asked: is it the case that in the social sciences the bar is lower because the risks are lower? Are things we built in historically – like confidentiality – protecting us? University standard consent forms are often about protecting the university. Another risk is that a 20-page consent document drafted by lawyers doesn't amount to meaningful consent, as it is unlikely to be read (although as another attendee pointed out, consent forms are usually quite short, with the participation documents being long). Several attendees described creative alternatives which "move beyond the paper":

- A "case of ethics": a travelling salesman case with different case studies of ethical problems which might arise with research. This was an engaging way to move beyond the paper.
- A graduate student who made a consent video for participants.
- Format of a card given to participants interviewed at a festival with key details, as participants would not be able to carry around papers at a festival. This made the researcher focus on the key things s/he wanted to communicate on a pocket-sized card, i.e. knowing you can change your mind/withdraw and who to contact.

One attendee suggested bringing people to conferences to "show them how we talk about them" – this was received well by the group. S/he suggested that in an ideal world, research would be a way of working and living that engages people in research. One example of this which already occurs is the ESRC

Festival of the Social Sciences. As one attendee put it, in non-medical research, the system you're in is life (as opposed to the hospital): research engagement should reflect this. The children we reach out to at festivals are the research leaders of the future. One attendee noted that GCSEs used to include more of a research component: now there's a shift back to Victorian fact learning rather than discovery-led education.

Returning to the subject of consent forms, attendees noted the differences and similarities with different research groups. For example, approaching drug-dealers with consent forms poses specific risks to researchers. On the other hand, participants who have learning disabilities are subject to a system of paternalistic gate-keeping. Researchers often need to meet them two or three times before they even start collecting data. This is partly to persuade the gatekeeper and partly to ensure informed consent. Communicating research outcomes is particularly difficult, as some participants may not understand what a book or paper is. Participants therefore agree not because of full information, but because they like the researcher and feel a personal connection with her/him. With all groups discussed, consent is always part of an inter-personal bargain. The verbal part of informed consent is key: it's never just signing paper.

The discussion then returned to the question of how much do you spell out benefits of participating versus risks? One attendee noted that participants can become disenfranchised as the research doesn't produce changes they were hoping for – particularly in her area of drugs research. This led her to err on the side of not selling the benefits. She also raised a troubling question: "who accrues more benefit?" Researchers tend to accrue more benefits than participants.

One way to address this is a commitment to better dissemination, as paywalled papers means participants cannot reach them. Another promising area is engaging participants as peer-researchers, and asking them about consent forms, questions, etc. This is another important difference between medical trials and qualitative research: in the former, the hope is that you can benefit directly. Attendees asked how communicating benefit works in engineering? One attendee raised the interesting example of anthropologists working with engineers to understand local culture and find less sacred sites for drilling in order to maintain good relationships with local communities.

Emotions and emotionality in research

Although avoiding harm and distress for participants is a common question in research ethics, this is less often asked about researchers, particularly those engaging in difficult or sensitive research topics.

One aspect of this is significant uncertainties in what might come up in qualitative research. Researchers can't know the background of each individual they're interviewing, and how they are going to react. For example, when discussing redundancy and precarity, the research prompts you to think about how these topics influence your own life. Another attendee gave the example of studying education access and having accounts of domestic violence and child abuse come out as a barrier to staying in education. This is particularly the case with creative arts intended to provoke an emotion/space for reflection. Set questions can be restrictive, but making things leads to defamiliarization, particularly creating something over a couple of weeks which allows participants to think about their lives.

For research participants, relaying such accounts can be cathartic. One researcher said participants occasionally told her it was an amazing experience to have space to talk and be listened to non-judgmentally for an hour. A strong aversion to distress can be problematic as it ignores catharsis. However, there is no mechanism built in to track effects after research prodding on sensitive issues. Where can participants go if something has been distressing or triggering? Participants should have support even if/especially if they back out, to avoid a negative experience without catharsis. Researchers

are guests in people's lives, yet when you leave to another institution, they have to deal with such emotions on their own.

We need better training and resources for early career researchers. Newer researchers often don't get access to what went wrong in previous research, as experienced researchers don't discuss the emotional burden of research. This could be put together in case studies. However, it may also be a matter for those teaching, training and hiring researchers to take charge of, rather than ethics review boards. The pushback is generally: who is going to pay for this? One attendee described graduate students looking at difficult questions like drug addiction and domestic abuse, who must wait three months for counselling, saying this "feels like an ethical issue." Is that a question for ethics regulators, or for health & safety regulators? This touches on defining the boundaries of the PRO-RES framework.

One attendee asked whether research ethics has already become loaded with other functions, such as:

- census function (how university finds out what it's doing)
- liability function
- reputation management function: examples "tabloid sensitive" research topics such as what constitutes sexual harassment among students. Although there is not a lot of methodologically sound research, universities did not want to approve research which included observing student bars as it might impact their reputations.

Attendees discussed the benefits of narrowing down and separating out different functions of research ethics from health & safety. Is ethics really about regulating research? Is this how EU regulates in a governance way? Who owns all this? Is it sector ownership – which is woolly?

One attendee outlined a fundamental change: ethics in the doing of research had conventionally been seen as a matter of the virtue of the individual researcher rather than institutional structure. He described an assumption of virtue in the researcher. One thing that upsets qualitative researchers is that there isn't a history of abuse in social science as there is in medical research. Other attendees pushed back on this, citing the examples of the Milgram experiments, the Stanford Prison Experiments, and Cambridge Analytica.

A related issue is that ethics review assumes the researcher has all the power. Yet many researchers have had people walk out or been asked out of field sites. This is research participants voicing a form of power through exit. Would it be more desirable to have an expectation of participation in social research rather than an expectation of refusal? One attendee argued that as research forms part of structures of accountability in society, people who benefit from society may have an obligation to participate in research to give an account of that benefit. This might parallel the argument for a positive obligation to participate in drug trials because they benefit all. Is social research a luxury, privilege, an add-on or something much more fundamental? Perhaps research participation should be treated more similarly to jury duty.

3.8.2. Qualitative Research with Digital Data

Qualitative research with digital data includes social media research, video analysis, in-game data collection, digital ethnography and digital storytelling. A key consideration here is that there is not always a clear boundary between digital and non-digital data. For example, if you audio-record a face-to-face interview, the data is in digital form for the time being though the encounter was not. If the data is transcribed into a computer, it is still in digital form; if that transcript is printed out onto paper, it is no longer digital.

In this subgroup, the discussion was focused on the following questions:

1. How can researchers pick good research topics when there is such an enormous amount of choice?
2. How can qualitative researchers recruit participants ethically in digital environments such as social media platforms, online groups, or multi-player computer games?
3. How can sampling be conducted ethically when access to the internet is often affected by gender, class, and geographical location?
4. Can qualitative research be conducted ethically in digital environments where participants may not have to reveal their identity or may not be who they say they are?
5. What are the ethical implications of participants' levels of digital skill?
6. What are the ethical implications of researchers' levels of digital skill?
7. How can we ensure participants' privacy when the public/private boundary is unclear?
8. How can we make ethical use of 'found' digital data, from tweets or Facebook comments to full-length videos on YouTube or Vimeo?
9. How can we ethically analyse huge and complex qualitative digital datasets?

This breakout session started off with an objective setting from which the group highlighted three key areas for discussion:

1. Conceptualising digital data and its usefulness for qualitative research
2. Public-private ethics considerations
3. Distinctions between ethics in medical and non-medical research

Conceptualisation of Digital Data

As a result of rapid evolution in the use of technology, digital data has now become widely available, thus providing greater access to a wide range of participants beyond the use of conventional methods. One of the attendees described how *"everyone now talks about digital data as the new oil that is being held by large groups like Facebook"*, but what does this mean in terms of research ethics and integrity? In terms of qualitative research, we conceptualised digital data as data obtained from publicly available digital platforms such as Facebook, Twitter, online forums and blogs. The majority of these platforms are owned by big companies otherwise known as Silicon Valley companies.

An important question was raised that if a policy maker wants digital data, why not go to the organisation (like Facebook) directly? Why go through the qualitative researcher? The reasons could be because of:

- Distrust in the companies - hence alternative and impartial sources of information may be valuable;
- Qualitative research might be able to discuss the findings in relation to social contexts and draw out meanings. However, digital data in qualitative research should be used with caution as it has the potential to lose meaning and misrepresent the contexts;
- Qualitative researchers are able to carry out independent work and be critical of these companies when/if needed.

Public-Private Ethics Considerations

There are obvious ethical issues around the privacy of digital data, particularly around ownership of the data. Although digital data are publicly available, we recognised that there is a public-private boundary which should be considered when conducting qualitative research using digital data. Who owns the data and what can it be used for? What level of privacy or publicity is allowed within a company's privacy policy? It is also important not to assume that privacy policy is uniform across all digital platforms as privacy settings can be different. Privacy boundaries and terms and conditions may also differ across different platforms. In essence, the public-private boundary in the use of digital data for qualitative research remains a grey area that needs to be critically explored.

In relation to this, the group discussed a case study of an experiment conducted in 2014 by Facebook in collaboration with Cornell University and University of California where user feeds were altered². This raised several concerns over the privacy rights of Facebook users and what is acceptable within the company's data policy. This case study highlights the intersection of ethics with other disciplines (in this case law).

Ethics in medical vs non-medical research

The discussions around this topic recognised that ethical procedures in non-medical research are predominantly based on a medical model e.g. risk assessment process in social sciences draws on biomedical ethics. Beyond social sciences, biomedical ethics also informs other ethics guidance across other scientific disciplines like computer science. While this has been the norm, it raises a challenge as the biomedical ethics model does not fit with qualitative research in the digital world.

Understanding people and contexts are regarded as trivial issues while technical/technology and biomedical research are generally perceived as being morally good. This perception legitimises biomedical research over non-medical research and has [inadvertently] engendered a reliance on the biomedical ethics review. Thus, we focused our discussions on problematising this reliance on biomedical ethical models and exploring alternatives which might be better suited for non-medical, particularly social science research.

The main problems are:

- The existing governance/ethics frameworks are not able to deal with the cross-disciplinarity between digital and social science research, which raises challenges when seeking ethical guidance from institutional ethics councils/committees;
- Informed consent: the biomedical focus on one-time informed consent does not necessarily work in digital research where consent might be required continuously or not even work altogether. It is also challenging to verify the identity of digital participants which brings the credibility of consent in digital research into question;
- Inconsistency of ethics considerations within and across countries which has implications especially for collaborative research

In exploring an alternative model that might be consistent with non-medical research, it is pertinent to separate the 'why' of the research from the 'how'. That is, the justification (why) of non-medical research needs to be clearly articulated but this is different from how the research will be conducted. Hence there is a need for reflexivity to provide clear accounts of the process. Though qualitative research is subjective,

² KRAMER, A.D., GUILLORY, J.E. and HANCOCK, J.T., 2014. Experimental evidence of massive-scale emotional contagion through social networks. *Proceedings of the National Academy of Sciences*, 111 (24), 8788-8790.

this transparency improves its reliability and the integrity of the data. Also, we can still learn from the biomedical approach to conflict of interest to protect the integrity of qualitative research.

3.8.3. Qualitative Data Analysis

Qualitative data analysis includes thematic analysis, narrative analysis, discourse analysis, conversation analysis, poetic analysis, visual analysis, mixed-methods qualitative analysis, and integration of findings in qualitative mixed-methods research. Ethical issues here include questions such as:

1. How can we maintain the integrity of qualitative data in analysis?
2. How can we juggle competing agendas during analysis, e.g. the agendas of funders, managers and participants?
3. What are the ethical issues in analysing visual data?
4. What are the ethical pros and cons of data analysis software versus 'by hand' analysis?
5. What are the ethics of interpretation?
6. What is the role of reflexivity in analysis?
7. What is the role of collaboration in analysis?
8. What are the ethical issues in reporting on qualitative analysis?
9. How can we spot ethical breaches in qualitative analysis?
10. What should we be concerned about given that others could misuse our findings?

Ethics matters during qualitative data analysis for several reasons. First, projects like Retraction Watch show us that ethics breaches frequently occur during data analysis: data is amended or falsified, analytic techniques are biased, findings are massaged or misrepresented. Second, qualitative data analysis is often conducted by researchers working alone; it is time-consuming and intellectually challenging; there are pressures from others' agendas. This complexity can cause errors at best, at worst unethical practice away from the gaze of others. Third, there are long-running debates about the quality of different qualitative data analysis techniques with the result that what some people regard as the ethical production of robust evidence may not be regarded that way by everyone. This applies particularly with more innovative methods such as arts-based analysis, but also applies to some extent to qualitative analysis across the board.

Qualitative data analysis is a poorly understood process, despite arguably being the most critical component of the qualitative research process. Contributing to that lack of understanding may be the lack of clear understanding of seemingly fundamental questions: What does ethics mean in the context of the integrity of qualitative data? How do researchers know what conduct is ethical in the analysis of qualitative data?

1. How can we maintain the integrity of qualitative data in analysis?

While it is difficult to propose solutions to maintaining the integrity of qualitative data, we can start by clearly identifying salient problems surrounding analysis. First, data files can easily be modified, intentionally or accidentally. Second, unconscious research bias may play an important role: data may be sorted in order to support a conclusion, intentionally or unintentionally.

2. What can we do to help ensure that qualitative data analysis is systematic, thorough, and robust?

Not addressed.

3. How can we juggle competing agendas during analysis, e.g. the agendas of funders, managers and participants?

Pressure from supervisors, colleagues, and funders (to name but a few) can put pressure on a researcher to come to differing, and potentially incompatible, conclusions. While there may be no immediate solutions to this particular problem, establishing clear and open communication with funders early in the research problem may help all parties to have clear and consistent expectations regarding the outcomes of analysis.

4. What are the ethical issues in analysing visual data?

During the analysis phase, visual data may be shared amongst many collaborators. An ethical question therefore arises as to how and if participants should be informed in advance both of how the data will be used, and how many people will see it. Attendees agreed that informing participants is the ethical course of action to take, but acknowledged that it can be difficult to ascertain what level of information is sufficient and useful. If the information is too broad, participants may not fully understand how their data will be analysed.

An effective measure proposed is to involve participants in the review process so as to comment on the collection and processing of the visual data.

A somewhat separate, but nonetheless critical, issue raised during the discussion of this question was the conflation of ethical conduct and legal compliance in the collection and processing of data. Ethical approval processes imposed by universities on researchers often focus on deflection of liability for the institution, rather than concern about ethical issues, leading researchers to mistake ethical conduct with legal compliance.

5. What about other sensory data e.g. sound, smell etc?

Not addressed.

6. What are the ethical pros and cons of data analysis software versus 'by hand' analysis?

Biases can influence the outcome of data analysis. Manual and automated analysis each present advantages and disadvantages. The researcher who performs manual analysis runs the risk of affecting outcomes with their own personal biases, but may also take conscious steps to correct it. By using software, the researcher removes their own biases from the process but may find themselves at the mercy of algorithmic bias if sophisticated software employing machine learning is used.

7. What are the ethics of interpretation?

All attendees agreed that the interpretation process requires a high degree of transparency when findings are published. Ideally, the method of analysis and findings should be published separately to ensure that the method used to derive conclusions is absolutely clear. However, attendees recognise that restrictions placed on article length and formatting by publishers do not always allow for an in-depth presentation of

methods. Furthermore, the method itself may not be novel or interesting, and thus fail to be treated as suitable for separate publication.

8. What is the role of reflexivity in analysis?

The role of reflexivity was only briefly touched upon in the discussion: All attendees agreed that it plays an important role in the process, but the topic was not discussed in depth.

9. What is the role of collaboration in analysis?

Collaboration undoubtedly has a significant role to play in the ethical analysis of qualitative data. Our participants advanced the following points:

- Collaboration could reduce the probability of researcher bias affecting outcomes.
- Collaboration with researchers from different fields could be highly beneficial because they bring different perspectives to the analysis of data, thereby helping to bring a broader perspective to the analysis as a whole.
- Involvement of research participants in the analysis could be helpful in order to mitigate ethical concerns around participant information.
- Supervision of senior researchers could provide additional insight and perspective on analysis.

Attendees recognised that limited resources and bureaucratic constraints are frequently significant barriers to collaboration. However, input from others through informal channels (e.g. colleagues, peers, doctoral students) should be sought whenever possible.

In the event that collaboration is not possible, attendees suggested the use of different frameworks to analyse data in order to provide different perspectives on the collected data and reduce the influence of bias.

10. What are the ethical issues in reporting on qualitative analysis?

Attendees raised the point that reporting is a significant issue when conducting organisational studies: Insufficient anonymisation procedures can lead to tensions in the workplace, and possibly retribution, if other members are able to deduce participants' identities from the final report. As such, it is very important to thoroughly anonymise data and adhere to the strictest standards of confidentiality possible.

Another issue raised in the course of this discussion is that there can be a disconnect between ethics committees and what research is, leading to miscommunications between institutions and researchers.

11. How can we spot ethical breaches in qualitative analysis?

A lack of accountability renders this problem difficult to address, as there are no real sanctions attached to breaches: at worst, articles are withdrawn from publications or rejected during the review process. Even if one were to imagine a world in which meaningful sanctions could be imposed, who should be responsible for doing so? It is unclear whether it should be the mandate of the researcher's academic institution, the publication, or perhaps an independent body. If sanctions were to be imposed, publishers are likely best suited to do so as they are in the best position to assess the entirety of the data and analysis prior to publication.

12. What should we be concerned about given that others could misuse our findings?

This question was not addressed due to a lack of time.

3.8.4 Open Science and Open Data

Open science and open data includes concern about how to reconcile conventional assurances to qualitative research participants that the data they contribute, in whatever form, will be handled in ways that protect their identity, and the growing demand that all data should be deposited in ways that allow unconstrained public access. This is thought to be an important safeguard against research misconduct, by allowing independent verification of analyses and conclusions. It creates a tension between long-established expectations of ethical professional conduct and new concerns for transparency as a means of promoting professional integrity. Ethical issues here include questions such as:

1. Could all qualitative data ethically be deposited in openly accessible repositories?
2. What principles could be applied in redacting data?
3. Would data need to be collected in different ways if there was an expectation of deposit?
4. What obligations do researchers have to the intellectual property rights of research participants – copyright in documents or in their own words in interviews?
5. What are the obligations of secondary users, who may approach the data with different skills and perspectives?
6. How far do original agreements with research participants apply to secondary users e.g on benefit sharing or protecting group secrets?
7. What obligations do secondary users have in relation to data transfer between jurisdictions?

It is important to point out that despite the benefits of open access, it can lead to predatory challenges due to institutional pressure to publish in open access, the gaming around REF, and fees which act as a barrier wall. This might result in some institutions and young career researchers being left out.

Although some funders provide funds for open access, there are pressures for researchers who don't have the necessary finances.

There are several pressures, internalised challenges:

- Some universities don't think about the importance of open access;
- Institutional pressures to go for high impact journals;
- There are impact issues as well.

Furthermore, publication is one of the primary routes for opening science and data and so open access publications and the issues around are, also, relevant. At this point, some guidance for researchers would be of value.

Many researchers are interested in access to knowledge; they therefore go either to datasets or databases. There is then the question of 'is open data and open science a necessity for today?'

Two primary reasons why open science is important:

- Integrity as it opens publication up to peer review;
- It also allows re-use of the data, which retrospectively benefits the society.

However, the problem is:

- What is meant by open?
- What is being opened?

Another issue is that some of the data isn't really opened because of a paywall.

The discussion was developed following the aforementioned list of questions:

1. Could all qualitative data ethically be deposited in openly accessible repositories?

Qualitative data throws up specific issues:

- How far do you go back in your processes to open up data?
- Are we talking about opening up audio, video, primary analysis, etc stage?
- There is always a concern about how intrusive research is. How much of this should be opened up?

2. What principles could be applied in redacting data?

There is also the issue of language. It impacts how the data is interpreted and analysed, and, also, the ethics of science communication, namely, how the research is interpreted by the general public. There needs to be something about the language of communicating research output to different audiences. There is also concern about how consent was obtained. However, not all qualitative research relies on consent, e.g. undercover police. But should it? Furthermore, psychological research, anthropological research, etc. in some cases do not require consent. Thus, when is consent inappropriate? And what principles or practice could we recommend to make consistent judgments about data gathering without consent? This is where a risk-benefit analysis could help. There is some benefit to broader groups. In some cases, the harms caused might be justifiable. On the other hand, consent is foregone when it is impractical to obtain e.g. when very large datasets are involved due to very large number of people.

Regarding consent the following question is, also, relevant: What is the public interest in foregoing consent? Who decides the public interest values? The corresponding answer is that the 'virtuous' researcher has the responsibility for doing the balancing of risks and benefits with some oversight from regulatory bodies

- When carrying out research in countries that have lived through totalitarian regimes, it is very difficult to get informed consent. E.g. in some countries, talking about personal lives is frowned upon
- In some other countries, the understanding of consent is questionable because of lack of understanding of what the research outcomes brings
- Asking the same questions in different countries, results in different answers due to environmental factors.

Other questions:

- How do you account for the power interplay between the subject and researcher?
- Contextual factors - The socio-environmental factors have an impact on the research.
- Field notes, audio recordings, etc; who has access to these?

Series of questions that a researcher should answer during the lifecycle of research:

- Is consent considered to be appropriate?
- What is the conversation you have with participants to explain what happens to the data being collected, who has access to this data?
- There is a concept of dynamic consent being proposed by some. But how is that possible?

With dynamic consent, the difficulty with this is that you can't withdraw it. We, also, need more thoughts about harms: for example, what are the harms that we are preventing or promoting?

3. Would data need to be collected in different ways if there was an expectation of deposit?

- What data need to be collected in different ways?

In some cases, serious harms could befall informants if these data fall into the hands of authorities. Furthermore, we should be pushing back on the ideology that anonymisation relinquishes responsibility of the researcher towards the participant. In some cases, because of population size it might be easy to re-identify the informant. It is therefore, important to consider how much data is put out there in the open. Additionally, in some cases, the researcher may not always be the best person to make an ethical judgment. There are examples of some researchers who make secret recordings which is quite unethical. What about institutional racism, or the risk of disclosure? In some cases, we collect anecdotal evidence which might be questioned ethically, so a lot would depend on what is being deposited.

It might be important to change expectation to obligation.

It is difficult to say what the consequences of research may be. Is it appropriate to say with the participant that you are taking a risk? Participants sometimes feel that they are protected.

What are the material risks of information harm in relation to research data collection and the participants?

4. What obligations do researchers have to the intellectual property rights of research participants – copyright in documents or in their own words in interviews?

- Is there a shared right between researcher and participant?

In universities, the university owns the data. The research has right to this data, but the university owns it. And the research funders have no right.

With open source, there are intellectual property rights issues like copyright of data in databases.

Inserting the word of 'ownership' cuts the link with participants.

But under governance, out of respect for legal liabilities, institutions prefer ownership.

- When you participate in research and give your time and ideas, do you have joint copyright holding?

5. What are the obligations of secondary users, who may approach the data with different skills and perspectives?

- In some social media research, participants have a right over what information they provide, but have no right over how it is interpreted.
- The closer the participant is to the data, the closer their rights are.
- In the case of raw data the participant has greater rights over that data. As it progresses through the research process, the researcher begins to assume greater rights;
- Perhaps it is the researcher's responsibility to provide contextual data to improve secondary analysis

6. What are the obligations of secondary users, who may approach the data with different skills and perspectives?

This opens up new question: Should there be a second review for every secondary use?

7. What obligations do secondary users have in relation to data transfer between jurisdictions? And, additionally, how do we ensure that the same ethical standards apply to secondary use as they do to primary research?

- How do researchers deal with different cultural expectations?
- Is research as a primary locus? Or with participants?
- It is obligatory for researchers to understand the risks. In some cases, participants expect completely open access to data, e.g. putting research data on YouTube.
- There are different expectations of research participants. It is therefore important to open up the discussion to participants and indicate the risks of their participation. You should not open up these risks beyond what one should expect in everyday life.
- Undertaking risk assessment is important. Do we need some template for risk assessments?
- Some template for extinguishing harms (harm mitigation)?
- There is need to support researchers in thinking about risks and potential harms.
- In terms of secondary notes, should field notes be open? The major worry should be about the environment in which qualitative research was conducted.

4. Identified elements to be covered in the framework per community of practice.

Since the framework will not be legally binding, it will need to be compelling, and to have cross-disciplinary relevance. It is important to get the different EC, and other, projects to talk to each other and co-construct a framework, to ensure continuity.

4.1. The importance of publishing negative results

Elsevier has launched the Publishing Ethics Resource Kit (PERK) in order to support journal editors in handling publishing ethics allegations. The PRO-RES tool could act as a «wizard», a computer interface that leads its user through dialogue steps, based on PERK. However, publishing scientific work is the very end of the process. Ethical issues need to be addressed at a much earlier stage. One of the most interesting developments is the strong push from the biomedical sector towards publishing more. It is a fact, however, that publishers do not favour publishing negative results, although such publications would be extremely helpful for other researchers. This means that a change in the philosophy of scientific or scholarly journals is necessary, so as to be more open to publishing negative results. On the other hand, there are several cases in which the researcher himself avoids publishing negative results, especially when these are the outcomes of funded research. We have to see in which journals we could publish negative results and push towards this direction. High-ranked journals must take the initiative to publish negative results.

In international collaborations, researchers must cope with differences between countries' cultures and their understandings of good practice. Clear guidelines are imperative if the research community is to address such issues. Theoretically, nothing prevents us from integrating different guidelines from different countries and continents. However, such guidelines should be adapted to European standards and needs.

In a broader sense, failure analysis is critical. We need acknowledgement of failure, and understanding of good failure, to help us innovate, as failure is not something to criticise but a great opportunity to learn that can help us avoid repeating mistakes. To that direction, a Journal of Ethical Dilemmas and Failures could be useful.

4.2. Young researchers

Young researchers should be targeted in the discussion. More specifically, we need to define how to motivate young researchers to conduct their experiments while taking ethical implications into consideration. Ethics must not be sacrificed in favour of fast publication (without cross-checking). When the output is the expected one, an experiment must be repeated in order to avoid unwanted bias. More and more European countries are establishing a rule for a minimum number of published papers in order for a researcher to obtain a PhD, which means that the pressure to publish gets more intense for young researchers. In fact, nowadays, there are criteria for PhD students that established academics might not fulfil. Simultaneously, there are multiple groups working at the same time and in the same field. This often leads to publishing without cross-checking. On the contrary, in the industrial sector R&D departments are obliged to conduct at least three replications in order to have reliable results. The actual problem is when competition becomes so strong that ethics do not become a priority. PRO-RES could focus on the training and education of young researchers in a way that ethics and integrity are always taken into account during scientific research.

It should also be noted that PhD research has to contribute to science. As long as it is novel, if it is based on high quality research, it should be considered equally important. Moreover, publicly funded research should be publicly acknowledged and available. Additionally, during the submission process of a paper, a researcher has the option to publish or not the relevant data. There are several cases in which researchers avoid publishing their data when such data are part of an ongoing project. These are issues that should be addressed from an Ethics and Research Integrity viewpoint. A solution would be to refer just to the best five published papers in order to describe a scientist's record. Such kind of approval would release some of the pressure for fast publishing. It could lead to more solid and reliable publications, and offer the researcher the necessary independence from supervisors.

In several universities, courses on Research Ethics and Research Integrity are taken at the beginning of the academic year in order for young researchers to have the right mentality. For instance, Karlsruhe Institute of Technology is part of the Helmholtz system, for which training of young researchers is of great importance.

4.3. The relation between working conditions and scientific results

There is already EU legislation on working conditions. Any practice that violates such legislation is illegal. However, researchers' working hours often derive from self-motivation rather than from bad practices by the employer. The example of USA could be followed where several laboratories operate on three 8-hour shifts. In the UK, for instance, even if someone is willing to work in a research laboratory during the weekend, this is forbidden for safety reasons. The meaning of 'forcing' people to work long hours should be clarified. The employer may not 'force' someone to work late, but the employee does not actually have a choice. A lot depends on what is happening inside research groups and on the attitudes and behaviour of the group leader.

During the last year in Greece, a new law was put into force which establishes and governs Research Ethics Committees within academic institutions. However, the law needs to balance flexibility and effectiveness. This can only be achieved by strong collaboration between researchers and regulatory bodies. Another problem in Greek academic institutions is the mentality of professors who do not give much opportunity to younger researchers. Within this context, the Government has to recognize the importance of legal responsibility and how this is allocated to senior professors, as they usually bear full responsibility for research projects in progress. Researchers in Germany, for example, seem to have more

autonomy. It is up to them how to conduct their scientific work, assuming that relevant guidelines will be followed at all times.

The main issue, at this point, seems to be how we train the young generation of researchers to have a good sense of research ethics and integrity. Otherwise we have to have regulations about everything. In a healthy working environment, each researcher has the opportunity not only to produce better results but, also, to prove his/her scientific worth. However healthy working environments and good results are not necessarily connected. A sense of safety may justify the social bonding of a research team, but beyond this bonding nothing can guarantee the quality of the research. They are related issues but they are not the same.

4.4. The Dual Use issue

Since PRO-RES covers both ethics and integrity, the implications of Dual Use when working on technology must be taken into consideration. For instance, research on advanced materials and nanotechnologies has this danger. The problem with this kind of research is that people who assign it usually ask for a technique without telling anything about its application. Nowadays collaborations are more open within the “Security” domain. In the past, for instance in 1970s-1980s, collaborations for bio-military purposes were forbidden. Now the issue of A.I. developments for military purposes is central.

4.5. The protection of privacy

The protection of privacy in the EU was highlighted in relation to both the new GDPR and Convention 108, which many European and non-European countries have joined, and the growth of state controlled surveillance, with its various components and implications for citizens’ privacy. There is still a great need for clarification of the relationship between ethics, privacy and the responsibilities of non-medical researchers.

Privacy, surveillance and covert research are all topics relevant to general research issues concerning the relationship between ethics and responsibility. This is a type of responsibility that must be exercised by the researcher from planning a project to disseminating the results, according to a path that requires taking decisions, inter-disciplinary dialogue, awareness of consequences, and the definition of limits. Therefore, the PRO-RES framework should cover the following aspects:

- Respect for the human rights of the people involved;
- Limitations on indiscriminate collection and use of information;
- The intended and unintended consequences of research activities and their impact on the researcher, the research participants, the research implementing organisation, those who use its results, the society as a whole;
- The division of responsibilities between all the actors involved in the research: the researcher and his/her research group (bearing in mind the diverse galaxy of researchers and the different types of research); the research organisation; the funding bodies; the institutions;
- Independence and freedom of research;
- Disclosure of possible conflicts;
- Reliability of results;
- Research as a common good of the whole society, which, therefore, has a public nature, of which the researcher must be aware;
- The proposal to consider researchers as public officials;
- The need to distinguish between what is allowed, what is legal, and what is ethical;
- The need to distinguish in the research the legal point of view from the ethical one, about the activities that can be carried out;

- Problems in ensuring that all steps of the research process are conducted ethically, especially when they involve setting up supply chains in developing countries employing national researchers and local governments (e.g., compliance to the UK “modern slavery act”).

4.6. Reliable research and policy making

Reliable research results, produced according to ethical rules and assuring the integrity of the researchers, can serve both the scientific community and society. In fact, the ethical conduct of research can help in re-establishing the societal trust in science and scientists, while on the other hand its results can serve the public interest in providing a sound knowledge basis for social and development policies. In this regard a number of specific points have been made:

- It is necessary to incentivise evidence-based policy making by incorporating reliable science into policy;
- There is a need for engagement of science actors in promoting an effective use of scientific results in support of EU policy making;
- The drive to be inclusive in bringing in different voices, besides scientists, when providing knowledge for policy making must not result in diluting expertise and being less rigorous in assessing evidence;
- Consider that even in evidence-based policy, there is not one single, one-directional option based on the evidence provided.

4.7. Qualitative Methods

A key question for PRO-RES might be what qualitative researchers can propose as an alternative to regulation via institutions as a basis for public trust? Much qualitative research can only survive on the basis of instantaneous ethical decision-making in the field and on strong assurances of the confidentiality of data. These are not easily reconciled with demands for institutional rather than personal accountability and for data transparency as the means of assuring integrity.

What would the world lose if qualitative research was shut down by ethics regulation? What sort of regulatory framework would allow qualitative research to continue?

The workshop highlighted different areas for considerations around ethics in qualitative research. Perhaps the most prominent of this is the issue of informed consent and its relevance in non-medical research. This calls for making ethical albeit subjective judgements which should not be the sole responsibility of an ethics committee. In fact, the researchers are best placed to make ethical judgements throughout the research process, so it is important to provide them with the right support through continuous training.

The group reached a consensus that a framework on ethics should include:

1. Concise statement around making ethics about ethics. The essence of this is to move issues that are not really about ethics out of the ethics purview e.g governance should not be part of ethics, also data protection is a legal matter and should not be considered as part of ethics.
2. Overarching theoretical framework to guide the PRO-RES framework unlike the Helsinki which is open without a guiding framework.

Qualitative Research with Digital Data

The discussion subgroup on Qualitative Research with Digital Data made, also, the following recommendations for the PRO-RES Framework:

- The PRO-RES framework should be designed as a dynamic process due to the rapidly changing nature of the digital world;
- It should highlight the importance of independent qualitative research in the digital world;
- The framework should focus on the ethical justification of the research/project and how it is being conducted;
- Ethical reflexivity and transparency on the subjectivities/subjective nature of qualitative research as opposed to quantitative research (dominant in biomedical research) where researchers claim an objective stance even though this might be influenced by subjective interpretations;
- Conflicts of interest are generally not considered in non-medical research so lessons can be learned from biomedical research;
- Recognise the private-public boundary and the current inconsistencies around what is regarded as private or public.

5. Possible solutions proposed by the stakeholders.

5.1. Science Journals and Publishing

Open access and open science present their own problems, if we recognize that they also create opportunities for predatory publishers, double-dipping, and making full costs of science communication fall on public funds rather than being shared by private or corporate users of that knowledge. While science, like all institutions, creates a particular distribution of rewards and incentives, some of these have become perverse, reflecting a publish-or-perish culture, created by the metrics used by funders and universities. If all we look at is a researcher's H-index etc., this will perpetuate the problem. National funders are looking into changing the reward system in science to address the underlying issues. We also need to see the relevant problems with incentives, impact factor, hyping reviews etc.

5.2. Institutional Structures

A lack of effective training at all levels, including supervisors and senior academics or managers, can perpetuate bad institutional practices. If there is no national agency supervising research institutions, organizations are tempted to cover up poor ethics or misconduct and to think that this is the best way to protect their interests. This is aggravated by the tendency to adopt quantitative rather than qualitative measures in performance evaluation because they are quicker and cheaper to administer.

5.3. Confidential Counsellors and Support Staff

It is extremely important to have someone to talk to, in confidence, about questions/concerns/issues affecting integrity or ethics. A formal channel for complaints, leading to official investigations is desirable but it is not sufficient. This needs to be supplemented by confidential counsellors and ombudspersons who can advise and support complainants.

5.4. Input on 'guidance framework' concept

5.4.1. What should a user-friendly framework to promote ethics and integrity look like?

- Positive approach; emphasise the fact that this is a good thing; present ethics and integrity as elements that should be taken for granted in future science and scholarship.
- Encourage the creation of guidance at a national level. If this is based on common principles, it should then be easier to harmonize the systems.
- A user-friendly framework has to be co-constructed with stakeholders. It should achieve two objectives: formulating overarching principles and ensuring applicability for every situation.
- A user-friendly framework has to consider its target addressees. It needs to take into account the entire research system, including individual researchers, research groups, policymakers, and funders. It may not be possible to have Europe-wide uniform frameworks immediately. A softer approach would promote convergence over time, with the consent and support of all stakeholders.
- The framework needs to provide a navigable route through complexity, between the regulatory 'floor' and the exploratory 'ceiling', focusing on the core values of honesty, care, fairness and respect.

5.4.2. What should its substantive content be?

There are excellent libraries of resources available, functioning as portals for anyone interested in research integrity, with links to materials published by other organisations. The following four are very

good, contain a lot of material and are kept up-to-date due to staff support investing time in them. They are:

- **NRIN** (Netherlands)
- **ENRIO** (Europe)
- **ETIKKOM** (Norway)
- Responsible Research | **Tenk** (Finland)

They contain

- codes of conduct
- policy reports on research integrity
- training materials
- research results and other insight-giving documents on the topic of research integrity.

Several Horizon2020-funded projects have delivered interesting deliverables, like PRINTEGER (Bonn statement) and ENERI, and more on the theme of Responsible Research and Innovation (SATORI, EnRRich, FoTRRIS, RRI Tools). New things are currently being built, such as an encyclopaedia of research behaviour (Integripedia, Netherlands). And, of course, there is valuable peer reviewed research about research integrity and ethics.

5.5. How to target key policymakers and have them endorse the framework?

- Suggestion that taxpayers, and by extension policymakers, should be interested in the framework since it is their money that is spent on research.
- Any documents need to be short (around 2 pages) to make sure policymakers are going to read it. It is also necessary to embed them in the process (including the European Parliament).

Four categories of targets:

- Individual researchers;
- Labs, PI's, research groups, mentors;
- Research performing and funding organisations, like universities;
- The system, ministries, those in charge of changing research performance indicators (and the publishing sector).

It is quite difficult to effectively reach researchers and PI's. Institutions already have considerable difficulty communicating to their own researchers, and European institutions will almost never be able to.

The discussion should be focused on how this tool will be useful not only for researchers but also for policy makers. We need to ensure that the right data are being used to make policy decisions. One of the major issues that a researcher faces is how to present their work in a way that is useful and meaningful for policy makers. For example, an online platform could be made available, where researchers could place a policy-focused summary of their papers, in order to maximize the likelihood them having an impact on policy making. In this way policy makers will be more easily informed about technological progress. We might ask whether we want the framework to define some of the roles of research scientists, what those roles might be, and what responsibilities might be associated with them. This brings the discussion to the assessment of impact of a new technology. For example, a policy maker would see not only what has been done, but, also, the impact of such a new technology. However, we need to answer whether each research group is responsible for making such an impact assessment, even if their research does not seem to have direct application. This is currently being debated In Germany, for instance: should research groups be assessed on their social impact as a dimension of measurements of their performance?

Another question is whether this framework would have any value without an authority to oversee whether or not it is respected and implemented. Such an authority (even appointed by the Commission), could perform an ethical audit for a research project to determine whether guidelines (derived from PRO-RES framework) have been followed. We need enforcement as well as encouragement for researchers to follow ethical guidelines. The current problem is how to convince researchers to see that there is an advantage to them from respecting ethics and research integrity. So, to the question “how the PRO-RES project can support specific needs and help to overcome current obstacles?” one answer could be to suggest some kind of penalties, not only for researchers, but for all people that are involved in publications: authors, reviewers and editors.

In fact, there are already punishments. For reviewers there is nothing official, but when unethical behaviour occurs, publishers ban reviewers (unofficially). A better approach would be to reward good behaviour, rather than punishing bad behaviour. However, we need a standard in order to establish what counts as good ethical behaviour. We need to find a way to make papers more «dynamic», adding for example a section for comments and feedback. This section of comments could be like an updated library. Journals have been reluctant to create such sections for reasons of cyber security.

Another discussion should be the ethics of the editors. In several journals, there is a lot of automatic rejection without peer review; for example, in cases where the author is “suspected of plagiarism”. Since this is identified by software, this decision is often correct, but not invariably. There are also ethical and integrity issues for editors when accepting a paper without peer review. This is mostly for editorial/introductory pages, but may (in principle) happen with any kind of paper.

There is a need to have some explicit criteria that editors should use in rejecting a paper such as manuscript composition, number of figures, word numbers, aggregation, citations. There should also be training for the next generation of editors. Young researchers and post-docs cannot evaluate papers without prior training in peer review, but this also applies to editors.

The question is, if there were a proper framework or tool guiding editors in proper ways to make decisions, would editors be willing to follow it? Each journal has its own specific criteria. Some pay attention to the authors’ status, while others emphasize the absolute quality of the paper or the interest of its findings. It would be difficult to create a framework/tool that is widely useful to many journals. At the same time, publishers should be able to keep their freedom of publishing only what they believe suits their objectives. Our goal must reconcile maintaining freedom within a common framework. There are cases where editors are asked not to reject a large amount of papers, but to try to find the optimal number to increase the impact factor. When journals become open access, the optimal point can change. After a transition to Open Access, the number of submissions from Europe usually decreased, those from China increased. Therefore, for the PRO-RES project, interaction with publishers is crucial. In China there is a huge pressure to publish and to be cited, leading to more pressure to commit scientific fraud. There are cases of e-mails offering money in exchange for citations. International competition has led to a lower quality level of publications based on the least possible effort. Publications are not competing to achieve the highest level. This is a huge integrity issue and shows that publication ethics and the interests of editors and publishers do not necessarily coincide. Each side has different motives. This has an impact on how researchers act.

Regarding covert research, it is acknowledged that, to a great extent, there are regulatory systems that establish very rigid prescriptive sets of procedures and then treat several typologies of research on public life as exceptions. What is required instead is a regulatory system that specifically addresses a vast range of non-medical academic research in its own terms and helps the researcher to conduct her/his activity in an ethical way within their own disciplinary field.

To this purpose a better conceptualization of the public sphere, in which observable activities of scientific and social import occur, is deemed necessary, as well as to establish the boundaries with the intangible private sphere. Such boundaries are by no means clear cut: there are activities carried out in the public sphere that can legitimately be considered private and activities occurring in the private, such as domestic violence, which have a fundamental public import and should be allowed to be investigated by researchers.

In this regard it is, also, to be considered that even when it is conceivable to collect it, the informed consent of participants does not always guarantee their safety and security. In many real life situations they cannot be aware of all the implications of their participation. Another paradox is that, in some instances, collecting consent requires the identification of subjects who would otherwise have remained anonymous, as in much observational research.

The guidance framework could provide a useful contribution to the democratisation of ethics and knowledge. The inputs received have been grouped into three areas: the format, the contents, and endorsement by policy makers. The workshops' participants expressed their favourable opinion on the format presented, which provides for differentiated access opportunities for the various types of actors in the research system, so that everyone can find appropriate indications, resources, operating procedures and tools.

In setting up the format it will be necessary to consider that there are different types of stakeholders, and that the framework will have to be able to address and involve each of them. An open format is suggested, which could allow interactions between researchers and the PRO-RES project to indicate resources and tools; as well as an update and control mechanism for the framework. Furthermore, it should be taken into consideration the importance of working on the language to be used in the framework, so as to have a simple and concise text, which can be understood and used by all the actors involved.

As a first indicator, the framework, in general, must deal with the following matters:

- How to deal with the large number of standards for research ethics produced in different fields, which sometimes conflict with each other, without making the framework excessively rule bound;
 - Values can be culture-specific and the rationale for their inclusion in the framework should be fully expressed and justified;
 - The challenge of relating values and principles to new ethical horizons opened up by technological and social innovation;
 - The differences between the disciplines and the fact that often each research group has its own values, principles and standards;
 - Awareness of the existence of conflicts between stakeholders about what counts as ethical scientific practice.
1. A flexible and transparent approach (avoiding rigid structures) was suggested. This should make the ethical decision-making process as explicit as that of the scientific process.
 2. Tools and resources should be provided to promote research ethics and support researchers in taking full responsibility for their work. The assumption is that good independent research provides useful information for the formulation of policies of general interest. In order to favour raising the awareness of researchers about their responsibility, it was therefore recommended not to provide a list to be followed slavishly (tick box list) or pre-compiled formats, i.e., based on a mainly formal approach. In this regard it was also suggested that the framework could

identify and indicate possible scenarios in research activities and provide different options for choice/operating procedures.

3. Ethical reflection is dynamic and must be present throughout the research process, from design to dissemination of results. Flexibility, process, reflexivity and transparency are all necessary.
4. The framework must take into account the differences between disciplines and the importance of interdisciplinary dialogue. The framework could promote cross-fertilization and mutual learning among researchers and institutional committees/ethics committees.
5. The definitions in the framework may not be shared (as in the case of ‘surveillance’) and the underlying concepts may be formulated in different ways.
6. The framework must take account of the new fields to which it may be applied such as internet research, artificial intelligence, machine learning, etc.
7. The framework should address issues related to the independence of research, including relations with funders, ideological influences, political pressures and possible sources of censorship.
8. The framework could address the issue of ethical impact assessments in order to promote anticipation of the possible consequences and risks related to research, provided that this does not become yet another administrative requirement.
9. The framework should address the relationship between privacy protection and GDPR.

The discussions highlighted a general issue of trust in science among policy makers. They need to have confidence in the appropriateness of information and knowledge (not always reliable). This must be taken into account in the framework design. The framework must show the advantages of ethics to all actors involved in scientific and technological research in non-medical areas (researchers, research managers, public and private research systems, and society as a whole). The framework should be addressed to the general public, while taking into consideration the diverse groups that the “general” public consists of, and aiming at enabling a ‘watchful’ society.

5.6. Broadening the scope of ethics and integrity

The notion of responsibility could be a realigning factor in broadening the scope of ethics and integrity of science. The drive towards responsibility could re-vitalize the way in which scientific actors see their ethical requirements. Ethically sound research and integrity in scientific practice are crucial ways in which scientists can demonstrate their responsibility. In this regard, the following suggestions are relevant:

- A clear distinction between ethics and integrity needs to be drawn; while ethics concerns more the way in which research can be conducted according with a “do no harm” principle; integrity concerns the quality of the research work, avoiding malpractices such as plagiarism, fabrication of data, etc.;
- The shift from a compliance focus to a responsibility focus in understanding and approaching research ethics requirements;
- Ensuring scientific integrity as a way to reinforce the value of knowledge production;
- Transparent ways to assess and ensure scientific integrity can be instrumental in rebuilding public trust in scientists and science.

5.7. The format of the framework

Regarding the format, it was agreed that the field to be covered was simultaneously vast and complex. This reinforced the project’s initial orientation to develop a resource-based framework that would be both flexible and contain in-built updating mechanisms. There was considerable discussion of how it might be best accessed and whether entry points should be based mainly on user roles. It would be necessary to strike a balance between a proactive, awareness-raising approach and providing some researchers and practitioners with easy-to-use templates and protocols. An implementation plan might also have to address institutional arrangements.

Some further specific inputs provided:

- Ensure the flexibility and permeability of the framework; consider using filters and gateways to facilitate access.
- The arrangement for entering the framework by role (e.g., researcher, reviewer, policymaker, etc.) would have the advantage of facilitating access to relevant resources, but could discourage those who do not identify with a single role.
- Avoid a “box-ticking” approach, but guide research actors to think about the ethical implications of their endeavour, in order to:
 - Encourage researchers to become more responsible and responsive (seeing the project as a starting point)
 - Induce scientists to use their own ethical judgement.
- Design the framework to provide an instrument that demonstrably meets the felt needs of researchers and other stakeholders (answering the “what’s in it for me?” question).
- Find effective ways to communicate the framework to the general public, addressing issues such as, whom do we target, how do we engage them, and for what.
- Provide mechanisms that address the complexity and scale of the field:
- Help users (researchers, policy makers) to have a sense of what is at issue, raise awareness and provide a navigational strategy.
- The framework should have tiered levels: I) values, principles, standards, etc., II) why these particular ones and where they come from? III) the underlying discussion, IV) the references and annotated bibliography.
- Do not hide the debate about what is in the framework.
 - Explicitly include research students among the users and address their needs.
 - Keep in mind the necessity of a clear framework easily applicable by practitioners and researchers, who do not have much time and sometimes actually look for templates and protocols.
 - Reconcile the need for templates and sample proposals with promoting reflexivity and discouraging “copy and paste” behaviours.
 - Consider setting up a group of people dedicated to respond to the queries (conditional on its sustainability).
 - Complement the framework with an institutional based implementation plan, foreseeing:
 - Institutional mechanisms at faculty or even lower levels (e.g., masterclasses on ethical protocols)
 - Institutional support to overcome the barrier of overload on the researcher
 - Consider other educational strategies around the notion of integrity, including the early education level.

Given that some of the current institutional frameworks are regarded as being not of the highest quality, it is doubtful that the PRO-RES framework can be built on all the existing ones, without discriminating among them. On the other hand, taking for granted the usefulness of a resource-based framework, the question remains as to how to go beyond somewhat narrowly focused codes to the broader responsibility issues. It is crucial to support the passage from ethics of requirement to ethics of responsibility (“why do I think that what I am doing is important?”). The extension from a “do no harm” ethics focus to a broader concern could be facilitated through the 4 RRI dimensions: anticipation, reflection, inclusion and responsiveness. The framework needs to be capable of adaptation to take into account the specific requirements of ethical research with different categories of human subjects (like vulnerable groups) and the diversity of contexts within which research can take place - specific contexts call for specific ethical requirements. The framework should include an array of different solutions for handling the ethics review process, illustrating which problems can be addressed by each solution. It should include procedures to deal with often neglected issues, like whistle blowing and redress for grievances. Ethical commitment

does not end with ethics review at the formulation and planning stage of the research: fundamental ethical choices may also be required in the field, especially when researching in difficult and risky contexts such as conflict areas or post-disaster zones. To that direction, it would be useful to have a centralised co-ordinated record of studies conducted in disaster and conflict settings, to avoid duplication and minimise research fatigue.

Some further, general remarks about the framework:

- A clear definition of ‘non-medical research’ is needed;
- General mission is to educate researchers as critical thinkers, rather than as blind followers of rules. The framework should provide guidance and enable educating researchers;
- Claims of authorship should come with acceptance of responsibility for misconduct;
- Awareness is really important, because “common sense is often not that common.” Example: four authors revised and published an article. At the final stage of the publication, two authors were gone and the paper had changed. It was a long fight with the editor to get the paper retracted although the journal’s guidelines were clear about that;
- Framework should be optional but tied to funding – researchers do not have to follow the framework if they choose not to, but they are not then eligible for funding. Accreditation as a gate keeper.
- The form and the content of the framework:
- Advice from ethical guidelines is often not easily acted upon. Researchers need actionable criteria, therefore applied research ethics and integrity is required. No need for academic jargon but illustrative examples instead;
- Case studies might help to apply the ‘rules’ and case-based reasoning might also help to guide researchers;
- To be actionable and have widespread use, the framework has to be very simple, like Isaac Asimov’s rules for ethical robots. It has to fit on one side of A4 otherwise it will not fly;
- Continuous assessment of ethical issues is important, but how? There are triggers when applying for project funding and reviews, but where are day to day places and times to discuss ethical principles (e.g. discussing authorship)?
- Where are points which are not obvious for ethical reflection? Maybe these can be used to get researchers engaged;
- Maybe it is reasonable to formulate easy statements such as “You should not cheat” and then go deeper in detail from there;
- Include pinpointing to unethical issues to clarify the principles;
- Easily applicable guides, e.g. for consent forms with easy statements, but as soon as the legal sphere is entered things get complicated. Consent in the form of checklist? User-friendliness is important also for research participants;
- The framework will not work for those who are not interested if it’s a lengthy document. There is no lack of information on ethical principles etc., but there is a lack of short, precise checklists with items to consider. Checklists are helpful; but have to be applicable for the specific field. Challenge – on one hand, to provide user friendly framework (for widespread use it needs to be 1 page); on the other hand, to provide more information than just principles or values, because interpretation might be problematic; but not too much information at once;
- Videos/podcast might help, e.g. with each key statement comes a 60-90 seconds multimedia resource (video or podcast);

- Questions that might be asked in a checklist: I will not use the data of my students and not put him/her on the paper. I will not cross-finance other projects with the grant, etc.;
- Chatbot for ethical issues might help to gather questions and quickly guide researchers to the right resources;
- It might help if the framework is a collaborative, interactive space from the beginning. There needs to be an opportunity for people to interact with others facing the same kind of ethical dilemmas;
- Resources provided need to go beyond those that support research planning and formal ethical approval;
- It is essential to include resources to help researchers look after their own safety;
- PRO-RES needs to recognise and acknowledge its own implicit assumptions and values in the framework, e.g. that there are such things as good or bad policy and research which may lead to public benefit or social damage.

5.8. Targeting Policy Makers

The discussion about targeting policy makers has been focused on two main issues. First, the actual difficulty is in involving them in the process of developing the framework and making the case for its usefulness to their purposes and concerns. Second, the issue is how to extend the notion of ‘decision makers’ to include all the actors able to make relevant decisions. The following specific observations were made.

1. Even good, ethically sound, research can be disregarded by policy makers if it contradicts or challenges their deep-set convictions and strategies.
2. Consider also partners from industry as a kind of policy maker and find ways to involve them, overcoming their common scepticism and impatience towards science ethics concerns.
3. Consider and engage also institutional people, such as research managers, that could facilitate and encourage the use of the framework.
4. Engage regional practitioners and policy makers and address their specific concerns, also in the context of smart specialisation strategy.

Regarding policy advice as an overall problem, it is important to recognize that the ethical issues are linked to the survival of the human species and our societies. And then the problem is how to deliver transformative change – how to transform the energy system for example? (Feed-in tariffs – e.g. decentralized German system, from four big energy companies to thousands of small local cooperatives.) What does the evidence suggest: Make people stakeholders in the politics of change – such as solar cells on all south-facing roofs. Changing the culture of how people see themselves involved in a change process.

For this to work, five elements are required:

1. Hi-level political engagement
2. Hi-level civil service engagement
3. Boardroom from major companies level commitment/involvement
4. Community engagement
5. Competent research/academic monitoring or evaluation.

If PRO-RES is to ‘work’ it has to connect to the full range of ‘involved’ communities and mean something directly to the public. The underpinning ethics is about collective security. Work with a language of

inclusion rather than exclusion. Social policy research currently appears disconnected from social policymaking – the academics are detached and removed. The language of research reinforces the sense of disconnection between researchers and communities. This is a challenge for the research community. Re-engage and ensure the ‘language’ is accessible and meaningful to all.

5.9. Broader use of the framework

The need for an ethical framework, where the legislation is only the basis, has been recognised. Indeed, the GDPR does not cover all the aspects related to data protection; thus, being GDPR compliant is only the first step. Other aspects to be considered are:

- *user-centric model*: it needs to work for the individuals who are using it.
- *substitute ‘privacy’ with ‘ethics’* (privacy is only one aspect)
- *provide examples of business models that are ethics-aware*; companies should understand that ethics adds value: an ethics-aware business is more trusted by customers; this implies that more users will use the company’s product/service (the reputation of a company plays a significant role in the acquisition and retention of clients); more users mean more data, and, thus, more money for the company. Indeed, all participants agree that access to data is one of the primary goals of each company. Ethics-by-design can help to gain access to data and to manage it in the best way.
- However, in addition to a new culture, we must also consider the problem that SMEs could not have enough resources to invest in beginning to change their perspective.
- An alternative model towards a less profit-centred concept of values is possible. This needs to have the following features:
 - *awareness* of people; both from users and people working in companies
 - to encourage the *interdisciplinary*
 - *public incentives* (generally speaking, there is no interest from companies)
 - *sustainability* (ethical environment is, in all respects, an environment that we need to protect)
 - *ethics-by-design*: ethics adds value; it is a resource rather than a cost. Clearly, some costs are necessary: to create an interdisciplinary team (e.g., legal experts for compliance with the law, social media expert for improving the communication of values, ethical philosophers for analysing the whole aspects, computer scientists for implementing solutions), to implement technological tools that help in explaining the behaviour of a black box and tools for ensuring privacy;

Explainability, as required by GDPR, is a tool that we need to understand how to use. The main characteristics that a good explanation should have are:

- *simplicity*: this is one of the most important properties. The simplest explanation, which requires a minimum cognitive effort to be understood, should be enough. You must be able to reason with the black box model you are going to understand and to keep all the concepts in your mind
- *truth*: this seems trivial, but it must be considered by-design; if an explanation is not true, probably there are some biases in the data. However, if you are visualizing advertising for a wrong reason, it is the classification process that is wrong, while the explanation of why you are visualizing the advertising is still correct.
- *symbolic*: an example is saliency maps, which are usually a good way to compare algorithms, but they are not symbolic since they only highlight areas or pixels involved in the classification process; transforming them in a more abstract explanation would be desirable

- local vs global? Different levels to have an explanation: when the explanation is local it is explaining only a single case, while the goal of a global explanation is to recap the overall logic behind a black-box model. The first case is easier for very complex models like neural networks, but to better understand the big picture we probably need something in between, a sort of *sub-global explanation*
- *given by causality*, not by correlation, or, even better, by counterfactual analysis or domain adaptation
- *reasoning and learning* at the same time, taking advantages of multiple data sources (e.g., classifying images using both pictures and captions)
- *actionable*: there is an intuitive element of human perception which is not explainable, or is very hard to model
- *high level* in order to have understandable explanations; this is strictly related to the symbolic property
- *trust*: we must rely on an explanation
- *deterministic* vs non-deterministic: a non-deterministic explanation could be easier to provide, but it implies that understanding the model is more difficult; in addition, it violates the property of simplicity and, probably, the trust. Consistency is also a fundamental property in real life: if a person asks for a medical opinion three times from three different doctors, the opinions must be similar if that person is to trust them.

6. Issues identified that might appear in the future

6.1. Research in international contexts

Science Europe: Several risks associated with international mobility, such as a potential lack of clarity about where funds come from and which national jurisdiction applies. Greater international mobility creates opportunities for bad researchers who have violated codes of conduct or guidelines to simply move country and apply for funding elsewhere if there are no background checks or if they are insufficient. To prevent this, contractual provisions and mechanisms to share information across funders are needed. Misconduct should be pursued by the original employer in the country where it happened. If there is no national organisation to supervise the whole of the system, there is a lot of temptation to game the system.

6.2. Technology Assessment

Investigating (and developing) matters that are interesting and useful, and funding this research. This includes the debate about funding sex robots/atomic bomb/designer baby/spying drone research. It might not make sense to have discussions about whether (it is ethical) to fund this research or not, based on the possible non-ethical implications the developed technology may have.

If profits can be made with a technology, if there is a market for it, it will be developed (if not by publicly funded research, then by industry). The borders of what we can do are, already today, in many fields much further than what we agree is desirable to do. Development choices for new technologies are ethical in nature, but they are taken more in innovative industry than in universities.

The real debate may be a parliamentary one, about whether or not to forbid the use of some new technology. This is an ethical debate and has a lot to do with technology and society, but in its essence, not to do with research.

6.3. Open Science

Science Europe stressed the need to change performance evaluation systems and rate researchers not just based on the number of publications or citations. What is needed is Open Science that benefits the researcher without intermediates. Recognise quality over quantity (create a review system that does that).

6.4. Vulnerability

UKRI raised the question of who should be considered a vulnerable group and in particular, whether children should be considered vulnerable. She pointed out that children have their own views and that not including them in studies might marginalise them. The harm done that way might be greater than the risk they would be exposed to if they were involved. Moreover, young disadvantaged adults might be much more vulnerable.

Regarding research in countries where there might be risks for researchers or participants, there are two possibilities:

- 1 – don't do it. Take the world and divide it into 'research possible' and 'research not possible' areas.
- 2 – check what are the specific conditions and safeguards that are in place to deal with these issues.

Furthermore, personnel changes in organizations operating in disaster and conflict areas can cause organisational memory loss. Lack of institutional memory can lead to difficulty in maintaining high ethical standards, so the PRO-RES has the potential to help to that direction.

There is real research fatigue in disaster and conflict zones, and as yet no measures in place to try to tackle this problem or the associated problem of research waste. Simultaneously, some areas are under-researched and this also needs to be addressed.

There are opportunities for disciplines to learn from each other, regarding how they deal with risk. It is the context that creates vulnerability, rather than belonging to a group.

We cannot know *a priori* the applications of a new technology. For example, 3D printing was developed as a laboratory demonstration in 1984, whereas the internet storm on the '3D guns' arose sometime in 2012. This means that it took a while to do so. To use the 'apocryphal' response to the question to the founder of laser technology, 'what good is your invention', the answer was 'What good is a baby?'. For new things, at the research level where ethics review applies, the answer is not obvious due to the extreme delay between lab and market.

Regarding the possible future issues that might appear in the field of nanotechnology/materials science, one question that needs to be answered is which the latest technological developments are and what potential ethical issues could arise from currently impracticable technology in the field of nanotechnology/materials science. For example, new ethical issues may arise related to Materials Informatics. Billions of Euros are spent on the digitalization of materials and ethical issues related to big data sharing and availability may occur. Additionally, taking the example of nanosafety, quite a lot of effort has been put on which kind of meta-data should be used in order to describe the data. Is there a positive opinion on whether meta-data can have a real impact on research integrity? Can we find a way of using the right meta-data to minimise research misconduct? At the moment, meta-data are at the point of publication, there are the citation meta-data and, then, as you are uploading data - usually as part of the end of a project, or to meet the funder requirements-, those meta-data are part of the product. But the research we are doing is actually moving to the beginning of the research circle, at the point of the research method design that you are already linked to, so that the meta-data become part of the data set. We are also thinking through pulling directly into instrument meta-data, calibration, curves,

checkings. All these meta-data increase the liability of the data set. We are pushing that quite strongly, using nanosafety as a case study. It is again a matter on how to incentivise researchers to do that, which requires a lot of time and effort. The data are taken up to a completely different area because other people combine and compare data in their expertise area. This can show impact on a wider range of fields for every achievement. So there is a push towards the wider sharing of data. This is also happening in the NanoCommons project which is a research infrastructure, looking at developing for nano-data curators.

Making data available should be considered as a step to the right direction. However, it could be in the near future for researchers to generate data that seems real but is not real (taking data from different papers, re-arrange them and present them as a new scientific result that doesn't actually exist). This revolution that we are experiencing in the field of data and meta-data is positive but it could possibly pose new scientific risks. One solution could be the development of online notebooks that directly extract the data from an instrument.

Another upcoming technological breakthrough that would pose ethical issues is Machine Learning. The problem is that the people that use it are not developers of such tools and they just try to combine different tools that have been developed from other people, for their own purposes. Many parts of these are like black boxes since not even the actual developers understand how they work. This lack of understanding of how it works propagates to the end-user ending up with some AI that cannot actually be supervised by people. So this is an ethical issue whether to trust these AI tools or not.

7. Wrap-up

An interesting output of the project would be the establishment of a spin-off company that can provide consultancy on ethical aspects. For example, performing audits in European funded projects in order to check whether ethical principles are followed. In order for such a spin-off company to be successful ethical guidelines that can be applied globally need to be established. Cultural differences among different countries and continents need to be respected. Indeed, multicultural issues need to be reflected in the framework. We need to provide deliverables that fit the framework programs of the EC, but taking also into consideration the various international multicultural aspects. PRO-RES project, as every EU-funded project has the same issue to address, needs to find a sustainability option beyond the end of the project. The framework needs to be used by the stakeholders even after the completion of the funding by the EC. What would be useful is a European independent authority that can verify ethical problems and provide solutions. First an ethical code would need to be established and then such an authority could verify breaches of the code. Such code would need to be «dynamic», being updated on a regular basis in terms of criteria and good practices.

During the workshops, further research areas were identified that are expected to be further investigated and dealt within the framework:

- Ethics in humanities: in historical research and biographical research (autoethnobiography);
- Ethics in artificial intelligence, machine learning, the human agent approach;
- Ethics in internet research;
- New technologies (such as, for example, the self-driving car) that make it necessary to take ethical decisions in advance of what happens in ordinary everyday life.

Another topic of discussion was the fact that the scientific development and technological innovation, together with the broader societal changes, pose new challenges to the science ethics systems. Recent advances in areas like Artificial intelligence impose the necessity to make ethical choices that hitherto were not required because what now needs regulation was simply not possible. The new technical solutions can make obsolete some procedural safeguards that had previously been perfectly adequate.

In this regard the following issues were highlighted:

- The drive to “push the frontiers” of ethics inquiry to incorporate new challenges and opportunities
- Interdisciplinarity becomes a key requirement in dealing with new fields of technological innovation (e.g. in the case of A.I.)
- The opportunity and risks of ethics by design in fields like that of A.I.
- the obsolescence of standard forms of personal data safeguards (such as data anonymization) in relation to the possibilities opened by the “big data” revolution
- The inherent complexity of the problems at hand and the awareness that there are no easy technological fixes.

7.1. Ethics assessment facing up to a broad agenda of responsibility

Substantive discussion was devoted to how the notion of responsibility could broaden the agenda of ethics assessment from its somewhat narrow focus on what was termed as the “no harm” perspective derived from the bio-medical context. Thus, it was debated how to bring among the core ethical considerations a broader interpretation of responsible research, confronting issues of societal and social relevance. It was suggested to adopt an exploratory approach to ethics that would proactively look for new ethically relevant questions pertaining to science.

In this regard the following considerations were made:

- Introducing the notion of broader benefit of research in the evaluation process
- The benefits of responsible behaviour might be seen more in the process than the outcome
- Responsibility extends to justifying why certain research should be carried out
- A social validation of results needs more consideration: responsible scientists should reflect on the implications of their results for social innovation
- Institutionalise ethics and responsibility in a co-creation perspective.
- The anonymity requirement of the personal data may be gradually more difficult to achieve in the future, as the AI developments might make the identification much easier;
- Do robots have to tell people that they are robots online (ethics of AI)?
- Suggestion to use 60-second video clips for the framework and pilot framework publication. Develop the framework further collaboratively, otherwise it is possible to make a product which is not user-targeted. It is advisable to test different designs for the framework. Role-based web-pages may not work;
- It is important to achieve applicability and user-friendliness of the framework – a more interactive and collaborative approach is needed that provides few guidelines to make lives easier;
- Ethics by design sounds promising for the framework;
- Ethics needs to be integrative and not considered a paper work;
- 24/7 helpline for ethical advice could be useful.

7.2. Qualitative Methods

7.2.1. Conventional data collection and art-based research

- The idea of consent: is informed consent actually informed? Although participants might sign a consent form, do they actually know how data will be used, e.g. informed consent forms note that the findings will be presented in an academic journal article or conference but if someone hasn't been to university and do not have knowledge of what such things involve, is it still informed consent?

Some strategies to get around this:

- Could take participants to the conference but this necessitates time and resources;
- Adopt creative strategies:
 - One participant created short films that explains the procedures
 - Another participant has a case of ethics with different compartments that explains the various elements typically in an informed consent form.
 - A third participant used small cards at a festival, instead of large consent forms, which were more likely to be kept and revisited later.
- Importance of research that builds trust -> not just getting something signed off but building relationships.
 - Emotions of researcher and emotions of participants are important
 - Lots of concern about harm to participants in the form of distress but distress is not always negative and can be cathartic
 - Challenging the idea that the researchers are 'in charge' of the interview or relationship. E.g., an interview can be led by the research participant
 - The extent to which relationship with researcher is personal – trust. This relationship has been institutionalized in a contract between participant and institution, and the researcher is just a vehicle for this contract.
- Reflecting on the legacy of medical ethics for social science. Bar for consent may be lower in social sciences than medical research
 - Social sciences more to do with consent and anonymity
 - Unlike medical research, social science research is unlikely to involve risk of death or serious injury
 - Social science has a strong institutional history of protecting identity
 - The 20 page consent in medical trials isn't as relevant to social science because they often involve very different kinds of research
- Regulation vs ethics
 - Research regulation has other functions hanging on to it that aren't always appropriate. With the framework, it is important to specify what is in or out of scope. E.g. applications being rejected supposedly due to ethics concerns when the real decision is a matter of censorship or reputation management.
- Accountability
 - Is research a privilege or fundamental to a democratic society and exercise of European values? Perception that research is for fun or hobby but research could also be framed as a necessary part of a functioning and well-informed society.
 - Mutual accountability for the benefits of participation in society.

- What are our fundamental assumptions about research and what implications do these have for ethics?
- Management agendas behind ethics: seen it in action but not communicated. How widespread is it? Few reported cases and not just in universities, in other institutions too.
 - Example of a case study where an institution does its own ethics to regulate who has ownership, what can and can't be said, shaping the aim of the research undertaken.
 - Consider for ethics framework: insist ethics is about ethics, not about insurance or censorship
 - Agendas need to be disclosed to move towards change

7.2.2. Qualitative research with digital data

- Characteristics:
 - Research that involves blogs, online platforms, forums, etc
 - Data tends to be owned by massive tech companies
 - Data blurs private and public
- Importance of qualitative research in this context
 - It is important that qualitative research is done in this context – research at the moment is mainly with big data which strips away context and meaning. Qualitative work can help address this imbalance.
 - Important to have independent work in this area to be critical of big technical companies.
 - Sites like Facebook are designed to be addictive and encourage overuse. Qualitative research that picks up and analyses how they are addictive and highlights the consequences they have for people is important.
- Problematisation of relationship between ethics protocol and dominance of bio-med ethics model.
 - Inherited box ticking.
 - Is this model compatible with digital data. E.g. what is/how do you get informed consent from social media users? Case: you could approach person on twitter for consent but how do you know they are who they say they are?
- Rather than thinking about how we can get informed consent, think about what is ethical conduct and how can we act ethically?
- What we could retain from the bio-medical model: avoiding conflict of interests
 - Digital world, small number of powerful tech companies, reliance on big companies which jeopardises integrity.
- Digital data can be more long-lasting, (platform vs overhearing a chat) -> 'digital data never dies'. Unique implications for ethics.
- Distinction between public and private. How might different ethics committees think about the distinction particularly with international companies? What difficulties do these create?
- One of the things that is not acknowledged is all data starts from being qualitative. Big data research has decoupled this relationship. Data isn't self-sufficient and spontaneously created. Important to clearly articulate that you cannot make sense of big data unless you know about the

process by which it was constructed. Qualitative research is a way to understand how something is constructed.

- Qualitative and quantitative divide is not always useful – sometimes better to think about how they interrelate.
- UK ESRC facilitating research with big companies and compromising impartiality. Garry King (Sp?) – Harvard political science, well known in big data (wanted to create a model of data-sharing that could be adopted by other tech companies). Bringing together 9 funders who contributed to initiative. Set up a way for researchers to apply for grants to do research with FB data which is made available via Social Science One initiative. Academic freedom, publish results, and protect user rights. Took longer, data released was less than promised. Led to lots of tensions, researchers couldn't do what they wanted to, FB didn't get what they wanted. Demonstrates issues that can arise with such collaboration. Big challenge for tech companies despite good intentions. Trying to find a way that researchers and tech companies can come together and do research – is difficult but important. Potential for a good model.
 - FB image problem, was not protective enough about data but now too protective.
 - The fact that this didn't work in the US context, still could be used.
 - For FB, they've released the biggest amount of data available for researchers.
 - Concerns about the transparency of the data selection.
 - Links to early 70s, social indicators movement, couldn't be done back then because the large data set/technology wasn't there. But the same kind of ethical issues were there. Tried to convince people it is useful to get large data set.
 - It's important to understand how the data was generated.
 - Vital case study.
- Image analysis – big research topic e.g. deep fakes. Issues encompassed here that will be important. Links to the difficulties of being able to verify online content.

7.2.3. Qualitative Data Analysis

- Data analysis is the dark art of research.
- How do people know what is and isn't ethical when they are analysing data?
 - Not much guidance on this.
 - For ethical committees, it is not an issue because there is little institutional risk and their backs are already covered.
- How do researchers keep up with the changing world of ethics? Recently, 429 sociology articles retracted, many due to duplication, which used to be common practice. Maybe sign that researchers aren't keeping up with changes in ethics.
- Who is accountable for analysis?
- Need to distinguish between deliberate and accidental modification of data.
 - Researchers make mistakes. E.g. with transcription -> you might not know such as in the case of outsourcing.
 - We might forget some data – cognitive biases.
- Things that can help:

- Involve researchers/participants/professionals with analysis but this involves time and money.
 - If you do research alone, show colleagues, use different theoretical perspectives and methods, etc.
 - For students, supervision can be helpful.
 - Presenting to people in different fields.
 - Key role for journal reviewers and editors to maintain integrity of research – last port of call.
 - Journal articles, not enough space to detail research process.
- How ethical is data sharing?
 - Did you have consent?
 - What do you tell participants about how data will be analysed? Do you tell them lots, some, do they care?
 - Conflation between ethics and compliance. Has GDPR made things more ethical?
 - Some researchers think ethics is a nuisance, waste of time.
 - Data analysis with software can be compromised.
 - Made by people.
 - Not all – NVivo is an exception.
 - Linguistic analysis tool potentially more biased.
 - Technology can change how we do analysis.
 - How do you make your data available for other researchers? Not all journals have data archives.
 - What makes research better?
 - Collaboration
 - Reflexivity
 - Education and training for researchers to know what is and isn't ethical. The fact that this is a question suggests that people didn't know enough.
 - Not enough accountability from doctoral students to senior researchers.
 - Accountability of researchers and ethical research: We are humans and we need to have some room in a framework that takes into account human error.
 - Reasons for retractions are often due to human error.
 - Ethics analysis -> study looking at agency in lives of drug dealers. Represented as harmful and problematic but also that they are doing bad things in social structure. What theoretical frameworks are we applying? Are we just trying to represent a group or advocate for them? **There is an ethical dimension to the choice of theory we apply.**
 - Obsession with duplicates is another legacy from the biomedical world. If you are doing a meta-analysis or something it skews results but in social sciences, perhaps, it isn't as much of a bad thing. Suggests that it can be acceptable to publish similar papers if it is in different journals that reach different audiences. Push back on the simplistic understanding of duplicate publication.
 - Reputational issues of analysis – Alice Goffman did widely applauded ethnography of black people and police. A law professor who had formerly been a criminal trial lawyer found elements

of research did not coincide with his experience and argued data was misinterpreted. This became a case of reputational damage for a university because of a disputed analysis. Undermines trust, undermines ability to do research – it's quite important how these are handled and dealt with. Lawyer's critique of cherry-picking data to fit a pre-existing theory or value position.

- Data analysis and archiving
 - Growing expectation for researchers to archive. Once something is archived, you don't know how people will analyse the data and whether they will be critical.
 - Archiving – ethical backup because people can look at the data. Is it enough to say “I'm going to look at my data through this theoretical perspective,” which means there are elements you are excluding because they aren't relevant (rather than challenging your presuppositions). **Most important is the transparency.** Readers might not know what was left out and why and how that decision has been made.
 - There is still an assumption that you can do positivist research. Owning your selectiveness and being explicit about the mechanisms which is an alternative to archiving everything.
- Archiving: if you archive something which gives others access to transcription only, then there is a risk it might be taken out of context through some people argue that it's better to just analyse a transcript without the context.
- Translated data – once it is archived, you can't check the quality of the translation.
- Whose responsibility for ethics of archiving – is it the ethical responsibility of the first researcher or the second researchers? What are the ethics of secondary analysis? Why is there not the same level of stringency for secondary data analysis?
- Reuse of data is ethical because it avoids waste.
- For the first researcher, it is important to avoid misrepresentation in analysis.
 - Not just data that didn't confirm hypotheses and does confirm. Strength of disconfirming hypothesis.
- UK data services quite open about the kind of research you can put in – won't make you un-redact it.

7.3.4. Open science and open data

- Open access publication puts multiple pressures on researchers.
- Increasing cost of open access creates issues – budgeting to publish in high impact journals.
- Gaming around REF – difficult for researchers to navigate ethically. Guidance would be of value.
- Open data:
 - Research findings vs research data
 - Findings: publications, disseminated results, ethics of disseminating findings and research outcomes to different publics. Policy makers' dislike for nuanced – prefers oversimplified and exaggerated – how can a researcher ethically meet the needs of different parties?

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- Data: what counts as data – raw (richness) then selectively capture in audio file or field note, issues of right become paramount/
 - Participant has right over raw data but as analysis proceeds – transcribing, etc, does that right pass over more to the researcher?
 - Recognise potential issues of ownership.
 - Problematises idea of data as property (seen as such by institutions), typically organisations see themselves as owning data which raises problems with open research archives.
 - Disputes between researchers and institutions about who owns the data.
 - More researcher training to navigate these issues.
 - Variation between expectations of researchers and participants.
 - Purpose the idea of brain work for discussion of the meaning of consent.
 - Issues of harm: context dependent e.g. cameras vs something more serious like domestic violence.
 - Insufficient understanding of harm – tend to talk about specific incident but no taxonomy, no categorizing framework.
 - Talking about harms and risks separately.
 - Potential harms can be identified and you can also talk about how you can minimize risk.
 - Person best placed to make this judgement is the researcher.
 - Ethics of dissemination and impact – e.g. bite sized chunks of information.
- Constraints of open access: funding. SAGE has been engaged in debates to move towards more open science so you need to think about the different structures within different disciplines.
 - Open access policy meeting in the future: should not cost additional money for institutions.
 - Recognizing the predatory journals – what is a reasonable fee for open access?
 - Making difficult decisions about which papers to fund for open access.
 - Do we need to think about the academic paper as a way to communicate with wider public? Or is it just for academics to talk with each other?
 - Myth: open access is for general public, NHS for nurses.
 - Data is open to whom? Different publics and researchers need to be making work available to them.
 - Opening access to readers may close it to writers.
 - Ethical dimension to vanity publishing – if you can pay for your publishing, then people will be more likely to publish.
 - Inequality in open access – if you aren't permanent, then open access publishing is not as accessible so people with short-term have run-off effects – can't archive, bias.
 - Journal article doesn't serve everyone – different forms of publishing.
 - The Conversation – a place for researchers to publish.
 - Open science being participated in with general public:
 - Platform: Enquire
 - Open University collaborated with BBC to launch massive platform called Citizen Science to gather data – several missions that were very personal didn't go through ethics because they were framed as missions. Internet allows different kinds of things to happen, different approaches to the definition of research which has subsequent implications for ethics.
 - Research for entertainment (e.g. documentaries, and reality tv) – consider ethical questions with these.

8. Lessons learned / Conclusions

Integrity and ethics are two different procedures, but they will both be incorporated in the framework. Integrity is related to bad behaviour (misconduct) and should be punished. Ethics cannot be considered as a bad behaviour and the implications are different. We cannot make ethics into red tape for research. We must start the process believing that the PIs of the projects that they have integrity (and can be trusted).

What is interesting is how the administrative convenience of a distinction between research ethics and research integrity is being promoted and accepted. This seems true of the UK science and technology parliamentary committees but was expressed by others at the relevant workshop. It's almost as if scientific integrity is 'just' about FFP.

There are differences between commissioned research, academic research, and internal organisational research. Commissioned research has to be done quickly, there is no time to embed into a context or a community. Academic research is slow, publishing takes ages and is more for the benefit of academics and institutions than for participant communities, operational organisations or the wider public. Internal organisational research has to compete for resources.

During the meetings the formation of an Authority to which the supposed breaches will be submitted for evaluation was suggested. As pointed out during the discussion, inappropriate behaviour is not so uncommon. Despite that, even in the cases that penalties are decided, the names of the researchers that behaved in this way are not made public. This leaves space for such researchers to carry on with unethical practices and does not make other people aware of the risk they might face in interacting with these researchers. A suggestion would be to report such cases to the authority and after the final judgement of the authority, the names are made available to the public so that everyone can be aware of who misbehaved.

The discussions were focused on four major topics: the research environment for young researchers, the use of data, the publication mentality and procedures, the characteristics of the RRI framework that will be built by PRO-RES.

8.1. Young Researchers

It was generally accepted that prior to monitoring and assessing any use of data and any publication procedures, it is crucial to educate and train young researchers towards an "RRI vigilant" mentality of research conduct, within the proper scientific working environment. This is actually a prerequisite that has to be promoted from the stage of the undergraduate studies, and continue throughout all levels of studies and research.

8.2. Publications

The discussions regarding issues of RI in the publications domain occupied significant time at our meeting. All the participants contributed with relevant experiences from their research environments, providing various examples of misconduct. We focused equally on the responsibilities of authors, editors and publishers. Their respective responsibilities need to be clear, and set out in the guidelines framework provided by PRO-RES.

It is obvious that the problems around publication procedures are a "hot" topic. Most of the time, the discussions ended up on this issue. However, this should not exhaust our contribution. The promotion of integrity should be broader, covering all stages of research.

8.3. Use of data

The proper use of data is relevant to all other topics discussed (educating young researchers, publication procedures). In some contexts primary data collection can be, or can become, highly unethical. In other contexts primary data collection can be extractive which is also unethical. Data quality is very variable from good quality to bad quality. These are real challenges for operational organisations.

Giving feedback to participants after research is very important. This can be hampered by ethics committee requirements to anonymise participants so the only option is to feed back to their community. Social media can help in some areas. However, people are often unaware of the potential risks and repercussions of using social media.

We should make as much use as possible of existing research and secondary data. Though re-using data can be difficult if the necessary consent hasn't been obtained.

Finally, it remains a matter whether we make any explicit reference to dual use implications or not.

Significance of qualitative research

All data starts from being qualitative. One cannot make sense of the big data unless you make sense of how it is being constructed. This is particularly important in the case of digital data where qualitative research can provide deep insights beyond the big digital data and qualitatively probe how the data was generated. Also, in conventional research settings, qualitative research is more than data collection as it can serve as a platform for building trusting relationships with research participants.

Problematising the ethics institutions

The current ethics appraisal system within the European Commission as with other institutions is problematic. This is because they are set up as an approval system, but it should be more of an opinion system.

Ethics of Data Collection

- Informed Consent: Is consent really informed? Often people would sign a consent form, but they do not know how the information is being used because there remains a discrepancy between researchers' expectations and participants' expectations around the meaning of consent.
- Issues of harms: there is no categorising framework/taxonomy for harms conducting non-biomedical research. Ethics applications highlight the issue of risk (which has its root in biomedical research), but this is different from harm. So, there is a need to understand what harms and risks represent in non-medical research.
- Conflict of interest: Avoidance of conflict of interest as an area to borrow from biomedical research.
- Accountability in data collection: Who is accountable for data collection – the researcher or the participant? Or the researcher's institution? This remains a contentious area that needs to be further explored.
- Social Science One project³: a case study was cited of a collaborative project involving nine funders who partnered with Facebook in order to gain access to digital data from their platform. The eventual data released was less than what was promised due to tension around Facebook's need to protect the privacy of their users and meeting the researcher's needs, and this is a major

³ <https://socialscience.one>

issue for tech companies. The EC can learn from the processes employed in this case study to access digital data or partnering with technology companies to inform the PRO-RES project.

Ethics of Data Analysis

There are minimal or no sanctions at qualitative data analysis stage, so researchers are, usually, not able to determine what is or is not ethical. However, involving others in the analysis process through a collaborative approach (e.g. expert professionals, supervisions), adopting multiple theoretical perspectives and transparency in the data analysis process can make qualitative data analysis more ethical. With the advent of technology in qualitative research, it is also important to be aware of ethical implications of data analysis software as they can be compromised.

Informed consent also comes into play in data analysis in relation to what level of information (if any) should be provided to participants in relation to data analysis. Do we provide information on how data will be analysed? Are participants interested in this level of information?

Ethics of Data Archiving and Interpretation

Qualitative data collection does not only rely on primary data. It has even been considered ethical to reuse existing data where possible. But this raises questions around who owns the data and how is archived data used or interpreted? Is data owned by the researcher or participant? The discussion around this was that research participants have right over the raw data, however at the stage of analysis this right becomes transferred to the researcher. However, this needs to be further problematised with regards to ownership rights for archived data as this raises a question of: do we need consent for sharing archived data? If so, whose consent?

In relation to interpretation of archived data, transparency about one's epistemological stance and theoretical position is also important. Research is inherently subjective and based on our epistemology. Even quantitative research is not free from underlying philosophical assumption which in itself is a subjective stance. Additionally, we have a moral obligation as qualitative researchers to be open to disconfirmation, that is, allowing the data to disconfirm rather than confirm our theoretical positions.

Ethics of publication

Researchers, especially those in academia, are constantly under pressure of publishing in REF-able journals but there is no guidance or support in this area. Coupled with this is the need to disseminate research outcomes to different audiences in an ethical manner to ensure their needs are met.

8.4. The framework established by PRO-RES

It was agreed that there is no need to establish new guidelines as there is an extensive amount of them already available, covering all the fields of research. The problem is that they are either fragmented or not grouped in an efficient and easily accessible way. Therefore, our main focus should be to aggregate them and provide them in a coherent and user-friendly way to the research community, as well as to the policy makers and general public. This could be done via a wizard or a platform that would be easy to use.

It is crucial to keep in mind that we need to deal with differences in research mentality among Member States, and that we have to find proper ways to balance and harmonize them. It is, also, important to take into consideration that the current research environment is extremely dynamic, international, and borderless. This means that we have to anticipate the complexities of development through the

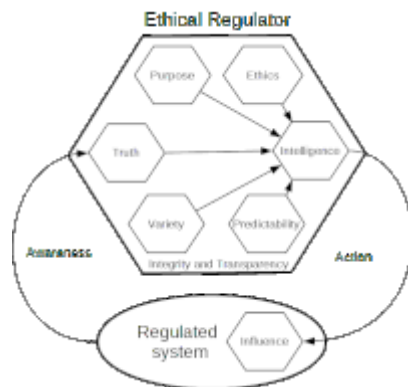
collaborations of researchers/RPOs of different Member States, as well as with entities outside Europe (e.g. USA, China).

Some further points:

- One additional question is how to deal with analysts/advisers in the public and private sectors rather than researchers (i.e. those who synthesise research, together with their own judgment/experience, to make recommendations, often behind closed doors). It would be very useful if they also followed guidelines etc but they would need to be adapted to their specific needs, for example research conduct is far less relevant, there are no ethics committees etc.
- Another question is how to incentivise them to use such guidelines. In the world of consultancy and advice, time is short and, unless you have to or unless it gives you a competitive advantage, you will not follow any guidelines. Public research money is not a sufficient driver as they rarely rely on this.
- The point about 'legitimate bias' (inevitable CoI etc.) in relationship to public policy research itself is an issue. In some respects it matches the problem we confront with journalism – even (or especially) with investigative journalism. There is the need to find a way of managing this in the guidelines and in the framework. It is, also, generally accepted that conflicts between values are inevitable, but adhering to some specific ones is needed. These should be set from the beginning; for instance, independence, transparency and multi-stakeholder working.
- It is crucial that any ethics guidelines in research take account of the variety of actors in that field, and do not exclusively focus on academic institutions but also involve other stakeholders. However, this will be difficult as they often face different incentives and are less dependent than academic institutions on public funding.

Annex a: Ethical regulator

From Wikipedia:



An ethical regulator and a regulated system

The **ethical regulator theorem**^[1] builds upon the good regulator theorem^[2], which is ambiguous because being good at regulating does not imply being good ethically. "The ethical regulator theorem claims that the following nine requisites are necessary and sufficient for a cybernetic regulator to be both effective and ethical:

1. Purpose expressed as unambiguously prioritized goals.
2. Truth about the past and present.
3. Variety of possible actions.
4. Predictability of the future effects of actions.
5. Intelligence to choose the best actions.
6. Influence on the regulated system.
7. Ethics expressed as unambiguously prioritized rules.
8. Integrity of all subsystems.
9. Transparency of ethical behavior.

Of these requisites, only the first six are necessary for a regulator to be effective. The three requisites ethics, integrity, and transparency are optional if a system only needs to be effective. This gives rise to the **Law of Inevitable Ethical Inadequacy**, which states "If you don't specify that you require a secure ethical system, what you get is an insecure unethical system." The reason is that unless ethical adequacy is a requirement, a system design will tend to optimize for effectiveness, and therefore maximally ignore the optional ethical, integrity, and transparency dimensions, which inevitably results in a design and subsequent implementation that is ethically inadequate and vulnerable to manipulation.

Effectiveness of a regulator

The ethical regulator theorem shows that the effectiveness of a cybernetic regulator depends on the strength or quality of six requisites. The effectiveness of a regulator, R, at achieving a given goal can be expressed as the function:

$$\text{Effectiveness}_R = \text{Truth}_R \times (\text{Variety}_R - \text{Ethics}_R) \times \text{Predictability}_R \times \text{Intelligence}_R \times \text{Influence}_R$$

If two systems, A and B, are competing for control of a third system, C, and Effectiveness_A "is greater than Effectiveness_B , then A is more likely than B to win control of C".

The effectiveness function reflects how the variety of actions that are available to an ethical regulator is reduced by all actions that are considered unethical, which puts an ethical regulator at a disadvantage when competing against an unethical competitor.

Annex b: List of participants

Workshop « Research funding and ethics »

Responsible beneficiary: EPC

Date: 13/11/2018

Place: Brussels, Belgium



No.	Full name	University/Organisation	Country	Capacity	Gender
1	Fabian Zuleeg	EPC	Belgium	Policy maker	M
2	Ron Iphofen	Academy of Social Sciences	UK	RE&RI expert	M
3	Helen Kara	Academy of Social Sciences	UK	Researcher	F
4	Jim Dratwa	European Group on Ethics in Science and New Technologies	Belgium	Policy maker	M
5	Filipa Ferraz de Oliveira	European Research Council	Belgium	Policy maker	F
6	Angela Liberatore	European Research Council	Belgium	Policy maker	F
7	Gabi Lombardo	European Alliance for Social Sciences and Humanities	France	RE&RI expert	F
8	Elaine Morley	UK Research and Innovation Strategy	UK	Researcher	F
9	Stephan Kuster	Science Europe	Belgium	Researcher	M
10	Kinga Sekerdej	National Science Centre	Poland	Researcher	F
11	Giovanna Declich	Conoscenza e Innovazione (K&I)	Italy	Researcher	F
12	Emmanouil Detsis	European Science Foundation	France	Researcher	M
13	Larissa Brunner	EPC	Belgium	Policy maker	F

14	Vidar Enebakk	Norwegian National Research Ethics Committee for the Social Sciences and the Humanities	Norway	RE&RI expert	M
15	Goeran Loevestam	Joint Research Centre	Belgium	Policy maker	M
16	Patricia McCann	Office of the Northern Ireland Executive Brussels	Belgium	Researcher	F
17	Jan Marc Roirant	Civil Society Europe	Belgium	Researcher	M
18	Juraj Koppel	Slovak Academy of Sciences	Slovakia	Policy maker	M
19	Gloria González Fuster	Vrije Universiteit Brussel	Belgium	RE&RI expert	F
20	Ruby Gropas	European Political Strategy Centre	Belgium	Policy maker	F
21	Eve Griffiths	Welsh Government EU Office	UK	Researcher	F
22	Frank-Dieter Fischbach	Conference of European Churches	Belgium	RE&RI expert	M
23	Natacha Faullimmel	European Political Strategy Centre	Belgium	Policy maker	F
24	Emira Kordić	Mission of Bosnia and Herzegovina to the EU	Belgium	Policy maker	F
25	Fairuz Mroueh	Oslo Region European Office	Belgium	Researcher	F
26	Gilbert Fayl	Former EC official	Belgium	Policy maker	M
27	Asaël Rouby	Luxembourg National Research Fund	Luxembourg	RE&RI expert	M
28	Roberta Monachello	Research Executive Agency	Belgium	Policy maker	F
29	Krista Varantola	ALLEA	Germany	RE&RI expert	F
30	Iina Kohonen	Finnish National Board on Research Integrity	Finland	RE&RI expert	F
31	Isabelle Nguyen	King Baudouin Foundation	Belgium	Researcher	F
32	Damian Patting	Conference of European Churches - Evangelische Kirche in Deutschland	Germany	RE&RI expert	M
33	Jack Harrington	Wellcome Trust	UK	Researcher	M
34	Karen Buchanan	Eindhoven University of Technology	Netherlands	RE&RI expert	F
35	Johan Bjerkem	EPC	Belgium	Policy	M

				maker	
36	Grace Spenser	UK Research and Innovation Strategy	UK	Policy maker	F
37	Yves Dumont	DG RTD – Research Ethics and Integrity	Belgium	Policy maker	M



Workshop «Tech Innovation»

Responsible beneficiary: NTUA

Date: 13/03/2019

Place: Athens, Greece

No.	Full name	University/Organisation	Country	Capacity	Gender
1	Hanshan Dong	University of Birmingham	UK	Researcher	M
2	Miltos Ladikas	Karlsruhe Institute of Technology	Germany	Researcher	M
3	Iseult Lynch	University of Birmingham	UK	Researcher	F
4	Marco Sebastiani	Roma Tre University	Italy	Researcher	M
5	Stefan Stanciu	Polytechnic University of Bucharest	Romania	Researcher	M
6	Alberto Tagliaferro	Politecnico di Torino	Italy	Researcher	M
7	Asterios Chatziparadeisis	Greek General Secretariat of Research and Technology	Greece	Policy maker	M
8	Georgios Tavantzis	YiotisS.A	Greece	Industry	M
9	Katerina Pissaridi	YiotisS.A	Greece	Industry	F
10	Dimitrios Dragatogiannis	National Technical University of Athens	Greece	Researcher	M
11	Aikaterini-Flora Trompeta	National Technical University of Athens	Greece	Researcher	F
12	Emmanouil Detsis	European Science Foundation	France	Researcher	M
13	Jean-Claude Worms	European Science Foundation	France	Researcher	M

14	Constantinos Charitidis	National Technical University of Athens	Greece	Researcher	M
15	Panagiotis Kavouras	National Technical University of Athens	Greece	Researcher	M
16	Eleni Spyrakou	National Technical University of Athens	Greece	Researcher	F
17	Vassilis Markakis	National Technical University of Athens	Greece	Researcher	M
18	Maritini Kalogerini	Innovation in Research and Engineering Solutions	Belgium	Researcher	F
19	Elias Koumoulos	Innovation in Research and Engineering Solutions	Belgium	Researcher	M

**Workshop « Surveillance, privacy and covert research:
current challenges to the research ethics and integrity»**

Responsible beneficiary: K&I

Date: 11/04/2019

Place: Rome, Italy



No.	Full name	University/Organisation	Country	Capacity	Gender
1	Marie-Sophie Peyre	ERCEA	Belgium	Policy maker	F
2	Joseph Cannataci	-	-	Researcher	M
3	Jeanne Mifsud Bonnici	University of Groningen	Netherlands	Researcher	F
4	David Calvey	Manchester Metropolitan University	UK	Researcher	M
5	Simon Dobrisek	University of Ljubljana	Slovenia	Researcher	M
6	Francesco Lapenta	Roskilde University	Denmark	Researcher	M
7	Chandana Mathur	Maynooth University	Ireland	Researcher	F
8	Maurizio Mensi	LUISS University	Italy	Researcher	M
9	Aitana Radu	University of Malta	Malta	Researcher	F
10	Paul Spicker	Robert Gordon University	UK	RE&RI expert	M

11	Emmeline Taylor	City University of London	UK	Researcher	F
12	Sveva Avveduto	National Research Council	Italy	Policy maker	F
13	Aygen Kurt Dickson	London School of Economics and Political Science	UK	Researcher	M
14	Bettina Zijlstra	Groningen University	Netherlands	Researcher	F
15	Anna Müller-Funk	Ludwig Boltzmann Institute of Human Rights and University of Wien	Austria	Researcher	F
16	Rocco Panetta	International Association of Privacy Professionals	Italy	Policy maker	M
17	Sara Helen Wilford	De Montfort University	UK	Researcher	F
18	Alfonso Alfonsi	Conoscenza e Innovazione (K&I)	Italy	RE&RI expert	M
19	Ron Iphofen	Academy of Social Sciences	UK	RE&RI expert	M
20	Claudia Colonnello	Conoscenza e Innovazione (K&I)	Italy	Researcher	F
21	Maresa Berliri	Conoscenza e Innovazione (K&I)	Italy	Researcher	F
22	Giovanna Declich	Conoscenza e Innovazione (K&I)	Italy	Researcher	F
23	Daniele Mezzana	Conoscenza e Innovazione (K&I)	Italy	Researcher	M
24	Fabio Feudo	Conoscenza e Innovazione (K&I)	Italy	Researcher	M
25	Paolo Signore	Conoscenza e Innovazione (K&I)	Italy	Researcher	M

Workshop « Ethics in the context of intelligent Decision Support, Autonomous Systems, Social Media and Bioinformatics »

Responsible beneficiary: TARTU University



UNIVERSITY OF TARTU

Date: 10/05/2019

Place: Tallinn, Estonia

No.	Full name	University/Organisation	Country	Capacity	Gender
1	Pekka Abrahamsson	University of Jyväskylä	Finland	Researcher	M

2	Karsten Boltz	Steinbeis	Germany	Researcher	M
3	Robert Feldt	Chalmers University	Sweden	Researcher	M
4	Rogardt Heldal	University of Bergen	Norway	Researcher	M
5	Ron Iphofen	Academy of Social Sciences	UK	RE&RI expert	M
6	Maarja Kruusmaa	TalTech	Estonia	Researcher	F
7	Liis Leitsalu	Estonian Genome Center	Estonia	Researcher	F
8	Gabi Lombardo	European Alliance for Social Sciences and Humanities	France	RE&RI expert	F
9	Kristi Louk	University of Tartu	Estonia	RE&RI expert	F
10	Ulle Must	Archimedes Foundation	Estonia	Policy maker	F
11	Mari-Liisa Parder	University of Tartu	Estonia	RE&RI expert	F
12	Dietmar Phahl	University of Tartu	Estonia	Researcher	M
13	Per Runeson	Lund University	Sweden	Researcher	M
14	Karl Smolander	Lund University	Sweden	Researcher	M
15	Magrit Sutrop	University of Tartu	Estonia	RE&RI expert	F
16	Katrin Velbaum	University of Tartu	Estonia	RE&RI expert	F
17	Claes Wohlin	Blekinge Institute of Technology	Sweden	Researcher	M
18	Barbara Weber	Technical University of Denmark	Denmark	Researcher	F

Workshop « Research ethics in disaster and conflict settings»

Responsible beneficiary: DCU

Date: 15/05/2019

Place: Dublin, Ireland



No.	Full name	University/Organisation	Country	Capacity	Gender
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1	Ayesha Ahmad	St. George's University of London	UK	Researcher	F
2	Gabrielle Berman	United Nations' Childrens Fund (UNICEF)	Italy	RE&RI expert	F
3	Anant Bhan	International Association of Bioethics	Canada	RE&RI expert	M
4	Fiona Brennan	Dublin City University	Ireland	RE&RI expert	F
5	Pat Brereton	Dublin City University	Ireland	Researcher	M
6	Kate Chatfield	University of Central Lancashire	UK	RE&RI expert	F
7	Anna Chimento	University of Liverpool	UK	RE&RI expert	F
8	Jocelyn DeJong	American University of Beirut	Lebanon	Researcher	F
9	Emmanouil Detsis	European Science Foundation	France	Researcher	M
10	Paul Eagan	Canadian Armed Forces (retired)	Canada	Researcher	M
11	Sheena Eagan	East Carolina University	USA	RE&RI expert	F
12	Lina Echeverri	European Masters in Disaster Medicine	Italy	Researcher	F
13	Oliver Feeney	UNESCO Chair in Bioethics	Ireland	RE&RI expert	M
14	Heike Felzmann	National University of Ireland Galway	Ireland	RE&RI expert	F
15	Sheri Fink	New York Times	USA	-	F
16	Martina Gustavsson	Karolinska Institutet	USA	Researcher	F
17	Kate Harvey	Nuffield Council on Bioethics	UK	RE&RI expert	F
18	Helen Kara	We Research It Ltd	UK	RE&RI expert	F
19	Su-Ming Khoo	National University of Ireland Galway	Ireland	RE&RI expert	F
20	Gabi Lombardo	European Alliance for Social Sciences and Humanities	France	RE&RI expert	F
21	Donal O'Mathuna	Dublin City University	Ireland	RE&RI expert	M
22	John Pringle	Médecins sans Frontières	France	RE&RI expert	M
23	Anna Skeels	Humanitarian Innovation Fund	UK	Researcher	F
24	Kelsey Shanks	Ulster University; UK Research and Innovation	UK	Researcher	F

25	Jack Taylor	Council of Europe Military Medicine	Belgium	-	M
26	Fiona Terry	International Committee of the Red Cross	Switzerland	Researcher	F
27	Nawaraj Upadhaya	HealthNet TPO Sudan	Netherlands	Researcher	M

Workshop « Ethics and RRI »

Responsible beneficiary: K&I

Date: 12/06/2019

Place: Brussels, Belgium



No.	Full name	University/Organisation	Country	Capacity	Gender
1	Wiebe Bijker	Maastricht University	Netherlands	Researcher	M
2	Axel Carlberg	Upspring Coaching & Consulting	Sweden	RE&RI expert	M
3	Mihalis Kritikos	Scientific Foresight Unit	Belgium	Policy maker	M
4	Esteban Pelayo	Eurada	Belgium	Researcher	M
5	Mark Sheenan	Oxford Biomedical Research Centre	UK	RE&RI expert	M
6	Luciano d'Andrea	Conoscenza e Innovazione (K&I)	Italy	Researcher	M
7	Ingeborg Meijer	University of Leiden	Netherlands	Researcher	F
8	Angela Liberatore	European Research Council	Belgium	Policy maker	F
9	Isidoros Karatzas	Director General for Research and Innovation	Belgium	Policy maker	M
10	Roxane Bibard	SoScience	France	RE&RI expert	F
11	Susanne Bühner-Topçu	Fraunhofer ISI	Germany	Policy maker	F
12	Nik Claesen	European Association of Research Managers and Administrators	Belgium	Researcher	M

13	Irene Doda	European Association of Remote Sensing Companies	Belgium	Researcher	F
14	Louiza Kalokairinou	Directorate General for Research and Innovation	Belgium	Policy maker	F
15	Veikko Ikonen	Technical Research Centre of Finland	Finland	Researcher	M
16	Daniel Trottier	Erasmus University Rotterdam	Netherlands	Researcher	M
17	Sara Helen Wilford	De Montfort University	UK	Researcher	F
18	Gabi Lombardo	European Alliance for Social Sciences and Humanities	France	RE&RI expert	F
19	Ron Iphofen	Academy of Social Sciences	UK	RE&RI expert	M
20	Maritini Kalogerini	Innovation in Research and Engineering Solutions	Belgium	Researcher	F
21	Maresa Berliri	Conoscenza e Innovazione (K&I)	Italy	Researcher	F
22	Giovanna Declich	Conoscenza e Innovazione (K&I)	Italy	Researcher	F
23	Daniele Mezzana	Conoscenza e Innovazione (K&I)	Italy	Researcher	M

Workshop « Ethics in finance and economics research »



Responsible beneficiary: EPC

Date: 19/06/2019

Place: Brussels, Belgium

No.	Full name	University/Organisation	Country	Capacity	Gender
1	Fabian Zuleeg	EPC	Belgium	Policy maker	M
2	Larissa Brunner	EPC	Belgium	Policy maker	F
3	Ron Iphofen	Academy of Social Sciences	UK	RE&RI expert	M
4	Caroline Gans Combe	INSEEC U Research Centre	France	Researcher	F
5	Ursula Huws	Hertfordshire Business School	UK	Researcher	F
6	Gabi Lombardo	European Alliance of SSH	France	RE&RI	F

				expert	
7	Jean-Claude Worms	European Science Foundation	France	Researcher	M
8	Fabio Feudo	Conoscenza e Innovazione (K&I)	Italy	Researcher	M
9	Francesco Lapenta	John Cabot University, Rome	Italy	Researcher	M
10	Nikos Kastrinos	Directorate-General for Research and Innovation	Belgium	Policy maker	M
11	Yves Dumont	DG RTD – Research Ethics and Integrity	Belgium	Policy maker	M

Workshop « Ethics, Social Mining, and Explainable artificial intelligence »

Responsible beneficiary: ISTI – CNR

Date: 08-09/07/2019

Place: Pisa, Italy



No.	Full name	University/Organisation	Country	Capacity	Gender
1	Vincenzo Ambriola	University of Pisa	Italy	Researcher	M
2	Denise Amram	Scuola Superiore Sant'Anna	Italy	Researcher	F
3	Bettina Berendt	KU Leuven	Belgium	Researcher	F
4	Agnese Bonavita	Scuola Superiore Sant'Anna	Italy	Researcher	F
5	Ann Cavoukian	Ryerson University	Canada	Researcher	F
6	Filippo Chiarello	University of Pisa	Italy	Researcher	M
7	Giovanni Comandé	Scuola Superiore Sant'Anna	Italy	Researcher	M
8	Cosimo Comella	Italian Data Protection Authority	Italy	Policy Maker	M
9	Mark Coté	King's College London	UK	Researcher	M
10	Alessandro D'Elia	University of Pisa	Italy	Researcher	M
11	Josep Domingo-Ferrer	Universitat Rovira i Virgili	Spain	Researcher	M

12	Maria Francesca Dona	SoBigData Operational Ethics Board	UK	RE&RI expert	F
13	Juan Duran	Delft University of Technology	Netherlands	Researcher	M
14	Roberto Esposito	University of Turin	Italy	Researcher	M
15	Alessandro Fabris	ISTI – CNR	Italy	Researcher	M
16	Daniele Fadda	University of Pisa	Italy	Researcher	M
17	Fabrizio Falchi	ISTI – CNR	Italy	Researcher	M
18	Andrea Gadotti	Imperial College London	UK	Researcher	M
19	Fosca Giannotti	ISTI – CNR	Italy	Researcher	F
20	Francesco Grisolia	University of Pisa	Italy	Researcher	M
21	Riccardo Guidotti	ISTI – CNR	Italy	Researcher	M
22	Andreas Hapfelmeier	Siemens	Germany	Industry	M
23	Ron Iphofen	Academy of Social Sciences	UK	RE&RI expert	M
24	Roberto Lattanzi	Italian Data Protection Authority	Italy	Policy Maker	M
25	Francesco Lapenta	Roskilde University	Denmark	Researcher	M
26	Giulia Lucherini	University of Pisa	Italy	Researcher	F
27	Andrea Mannocci	ISTI – CNR	Italy	Researcher	M
28	Letizia Milli	University of Pisa	Italy	Researcher	F
29	Anna Monreale	University of Pisa	Italy	Researcher	F
30	Mirco Musolesi	University College London	UK	Researcher	M

31	Michela Natilli	University of Pisa	Italy	Researcher	F
32	Francesca Naretto	University of Pisa	Italy	Researcher	F
33	Dino Pedreschi	University of Pisa	Italy	Researcher	M
34	Roberto Pellungrini	University of Pisa	Italy	Researcher	M
35	Ruggero Pensa	University of Turin	Italy	Researcher	M
36	Leonardo Piccini	IRPET	Italy	Researcher	M
37	Michele Piccinno	University of Pisa	Italy	Researcher	M
38	Nicola Picchiotti	University of Pavia	Italy	Researcher	M
39	Fabio Pinelli	Vodafone Italy	Italy	Researcher	M
40	Francesca Pratesi	University of Pisa	Italy	Researcher	F
41	Giovanni Puccetti	University of Pisa	Italy	Researcher	M
42	Roberta Radini	ISTAT	Italy	Researcher	F
43	Andreas Rauber	TU Wien	Austria	Researcher	M
44	Salvatore Rinzivillo	ISTI – CNR	Italy	Researcher	M
45	Vittorio Romano	ISTI – CNR	Italy	Researcher	M
46	Salvatore Ruggieri	University of Pisa	Italy	Researcher	M
47	Fabrizio Sebastiani	Facebook	UK	Researcher	M
48	Manolis Terrovitis	"Athena" Center	Greece	Researcher	M
49	Massimo Tosato	Cloud4Wi	USA	Researcher	M

50	Roberto Trasarti	ISTI – CNR	Italy	Researcher	M
51	Pinelopi Troullinou	Trilateral Research Ireland	Ireland	Researcher	F
52	Franco Turini	University of Pisa	Italy	Researcher	M
53	Michael Veale	University College London	UK	Researcher	M
54	Bruno Voisin	ICHEC	Ireland	Researcher	M

Workshop « Ethics in economics and finance research »



Responsible beneficiary: EPC

Date: 21/11/2019

Place: Bristol, UK

No.	Full name	University/Organisation	Country	Capacity	Gender
1	Fabian Zuleeg	EPC	Belgium	Policy maker	M
2	Ron Iphofen	Academy of Social Sciences	UK	RE&RI expert	M
3	Ian Roderick	Schumacher Institute	UK	Researcher	M
4	Alan Simpson	Advisor	UK	Policy maker	M



Workshop « Ethics, Integrity and Qualitative Methods »

Responsible: AcSS

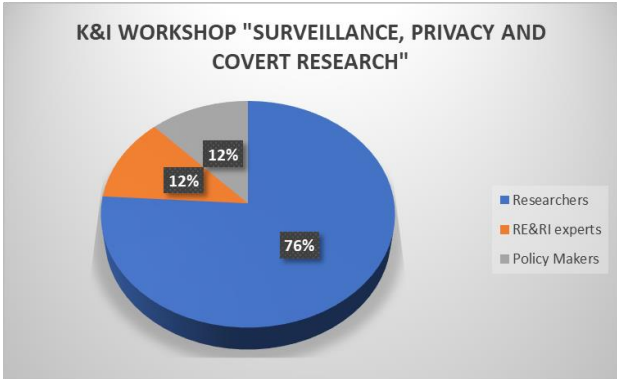
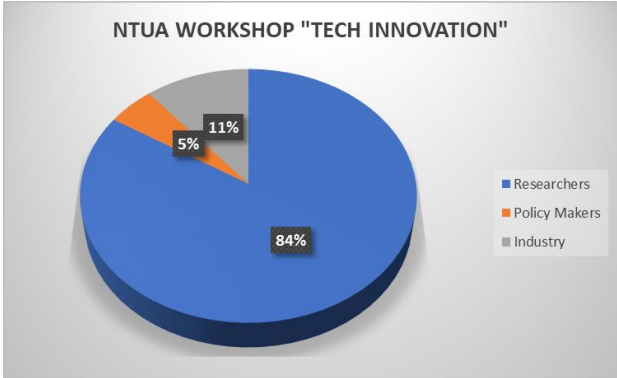
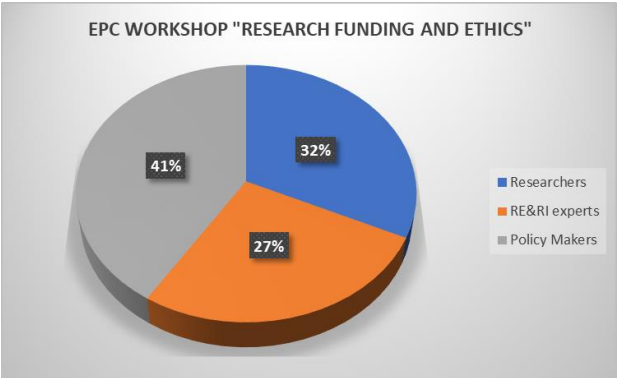
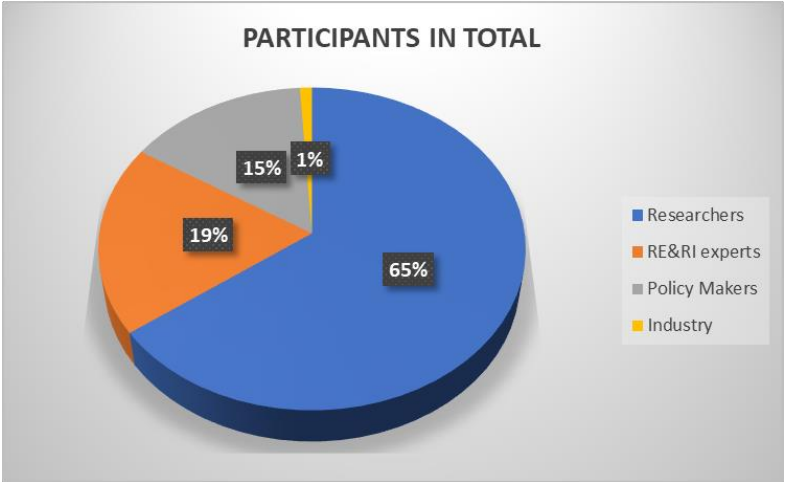
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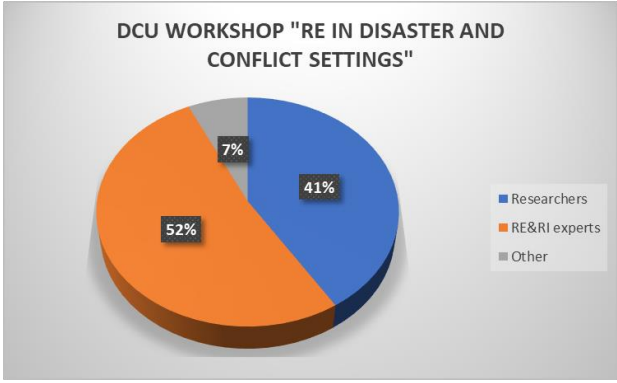
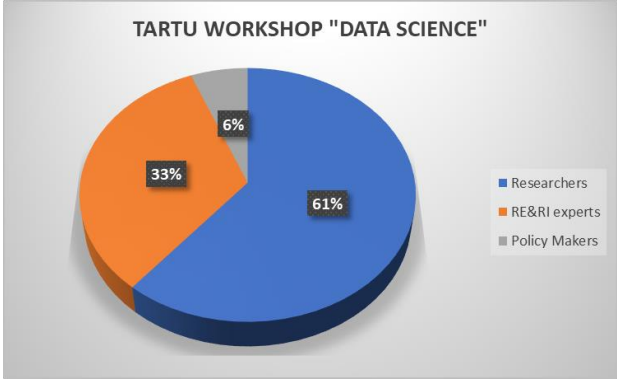
Place: London, UK

No.	Full name	University/Organisation	Country	Capacity	Gender
1	Robert Dingwall	Independent researcher/Nottingham Trent University	UK	RE&RI expert	M

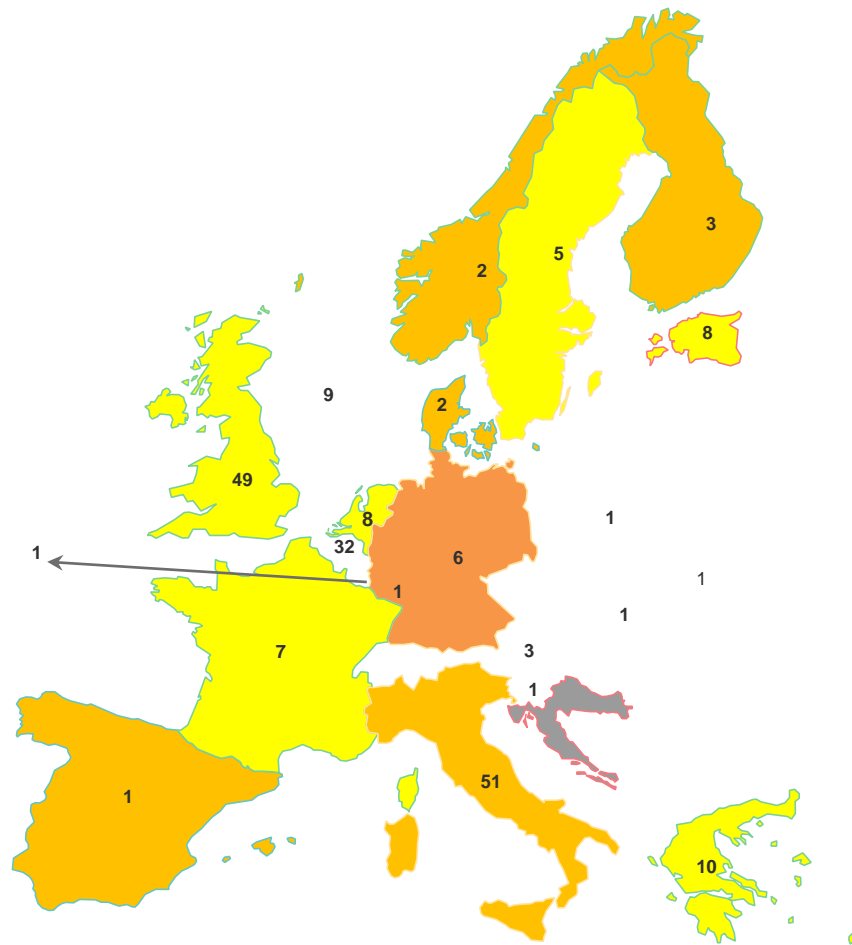
2	Helen Kara	Independent researcher	UK	Researcher	F
3	John Oates	Open University	UK	RE&RI expert	M
4	Ron Iphofen	Academy of Social Sciences	UK	RE&RI expert	M
5	Lucy Pickering	University of Glasgow	UK	RE&RI expert	F
6	Carine Vassy	EHESS/ Paris XIII	FR	Researcher	F
7	Dawn Mannay	Cardiff University	UK	Researcher	F
8	Helena Webb	University of Oxford	UK	RE&RI expert	F
9	Edward Dove	University of Edinburgh	UK	RE&RI expert	M
10	Dirk Vom Lehn	Kings College London	UK	Researcher	M
11	Bernd Stahl	De Montfort University	UK	RE&RI expert	M
12	Beverley Gibbs	University of Sheffield	UK	Researcher	F
13	Linda Hantrais	Loughborough University	UK	Researcher	F
14	Rob Street	Nuffield Foundation	UK	Researcher	M
15	Jennifer Evans	HEFCW	UK	Policy maker	F
16	Julia Slupska	University of Oxford	UK	RE&RI expert	F
17	Claudine Tinsman	University of Oxford	UK	Researcher	F
18	Jessica La	Kings College London	UK	Researcher	F
19	Deborah Ikhile	Nottingham Trent University	UK	Researcher	F
20	George Ogoh	De Montfort University	UK	Researcher	M
21	Katie Metzler	Sage Publishers	UK	Researcher	F

Annex c: Types of participants per workshop and in total





Annex d: Geographical distribution of participants



Annex e: Gender balance

