

PRO-RES

PROMoting ethics and integrity in non-medical RESearch

Deliverable Title: **Online Consultation process
results**

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Introduction

This survey was the objective of deliverable D2.4 Online consultation. The purpose of the survey was to reach a wider community than the phase 1 workshops, as it was promoted to as wide a list of stakeholders as possible. However, the response rate to the survey was very low and as such, the survey population cannot be deemed representative. The survey was sent out to 830 potential participants, utilising the PRO-RES stakeholder list and SurveyMonkey, as the online survey tool and MailChimp as the service to send the invitation to all the stakeholders, cognisant of the (recently established) GDPR regulations for emails. The survey received 28 responses, a very low response rate of ~3%, which is well below an average of ~20-30% to be expected for e-mail surveys. The issues addressed in the questions reflected the state of thought of the project regarding the PRO-RES framework (it was still not separated into an Accord and Toolbox at that time).

Email invitation

The message that was sent out consisted of the following message:

Dear [NAME],

I am contacting you on behalf of PRO-RES, an H2020 project that deals with ethics and integrity in the non-medical research. We are conducting a brief survey, in order to canvas the opinion of the wider community and we would like to invite you to take part in this effort. The survey should take 10-20 minutes to complete and can be found [here](#).

I also include in this message some more information about the project for your convenience.

PRO-RES is a project funded by the European Commission aiming at

PROMoting ethics and integrity in non-medical RESearch.

Our main goal is, with the aid of a full range of stakeholders, to devise and build a supported *guidance framework* for all non-medical sciences and humanities disciplines adopting social science methodologies. The framework will meet the highest standards of research ethics and scientific integrity and be comprehensive, covering the full range of issues and concerns – such as dealing with innovative technologies and the novel research possibilities of big data, the challenges of social media research and balancing public interest concerns with cherished rights to privacy. It will be of practical help in guiding interested parties to ways of achieving reliable and trustworthy research.

WHY IS SUCH A PROJECT NECESSARY? Trying to behave ethically and with integrity when conducting research can prove to be complicated given the wide range of codes, guidelines and frameworks. Regulations are diverse and inconsistent, and review practices vary considerably – between countries, institutions, disciplines and professions. As multinational and interdisciplinary research grows, it is vital that the confusion arising out of such disparate approaches should be reduced as far as possible.

We believe that sound, reliable, transparent research, not driven by ideology or subservient to it and undeclared vested interests, produces robust evidence that can benefit social wellbeing and societal progress. It is in the interests of the scientific community to ensure the evidence produced is reliable and trustworthy and ethically generated. It is in the interests of those who make policy to be able to assure the decision takers (and the general public) that evidence has been generated in the best possible way.

Survey Questions

The following sections outline the survey questions and indicate the form of answer that was requested. There were 3 sections to the survey (question sets), that were featured in separate pages on the online survey. Each section had a small introductory text as well.

Question set 1: Some information on the research field

1. In which country are you mainly employed? (list of countries)
2. Does your research involve issues that deal with (multiple selection with the PRO-RES topics plus box for "OTHER")
3. Have you had to go through some form of ethics assessment or appraisal when applying for funding or before beginning research following a successful application? (yes/no)
4. What form did it take? [checklist, questionnaire, ethics committee, (other)]?
5. Are you confident in your ability to write an ethically sound research proposal? (yes/no)
6. If not, why not? (free text)
7. Have you used 'ethics advisors' in your research? (yes/no)
8. If yes, where they in-house or external consultants?

Question set 2: The moral responsibility of researchers

Being a 'good' scientist in both the moral and methodological sense is not as easy as it might seem. All researchers have to compromise, make choices and balance potential conflicts and contradictions. Conducting research requires a balance between many political, institutional and professional contradictions and constraints

All questions in yes/no form or a agree/disagree scale and a free text explanation box

1. Should all research be conducted with formal ethics approval or an opinion from a research ethics committee?
2. If no, in which cases can formal ethics approval not be applied?
3. Do you agree with the statement "Demands of policy should be fully apart from the responsibilities of scientists/researchers?"
4. Do you agree with the statement that "...the freedom to conduct scientific research must be matched by enabling those affected by the research the freedom not to be obliged to be party to it?"
5. Do you agree with the statement that "...the benefits of living in society are such that people should have a duty to take part in research that does not expose them to undue risk"
6. Do you agree with the statement that "An underpinning by high quality research and evidence, including policy appraisals and evaluations, is a pre-condition for evidence based policy/decision-making, and hence rational policy actions and outcomes"?
7. Do you agree with the statement "All individuals and institutions involved in collecting and using evidence in policy making should be transparent on how the high quality of that evidence is assured and flag up any potential COIs"?
8. Do you agree with the statement "The independence and integrity of individuals responsible for the gathering of research evidence and its use in policy-making must be respected and supported in ways that ensure the evidence they produce is neither biased nor misleading"?
9. Do you agree with the statement "Under a commitment to evidence-based policy, all evidence should be based on ethically sound research"?
10. In your opinion, is the concept of *responsible research and innovation* (RRI) hindering or helping research?
11. Does the researcher have any responsibility for unintended consequences?

Question set 3: Ethics and your area of research

(all free text answers)

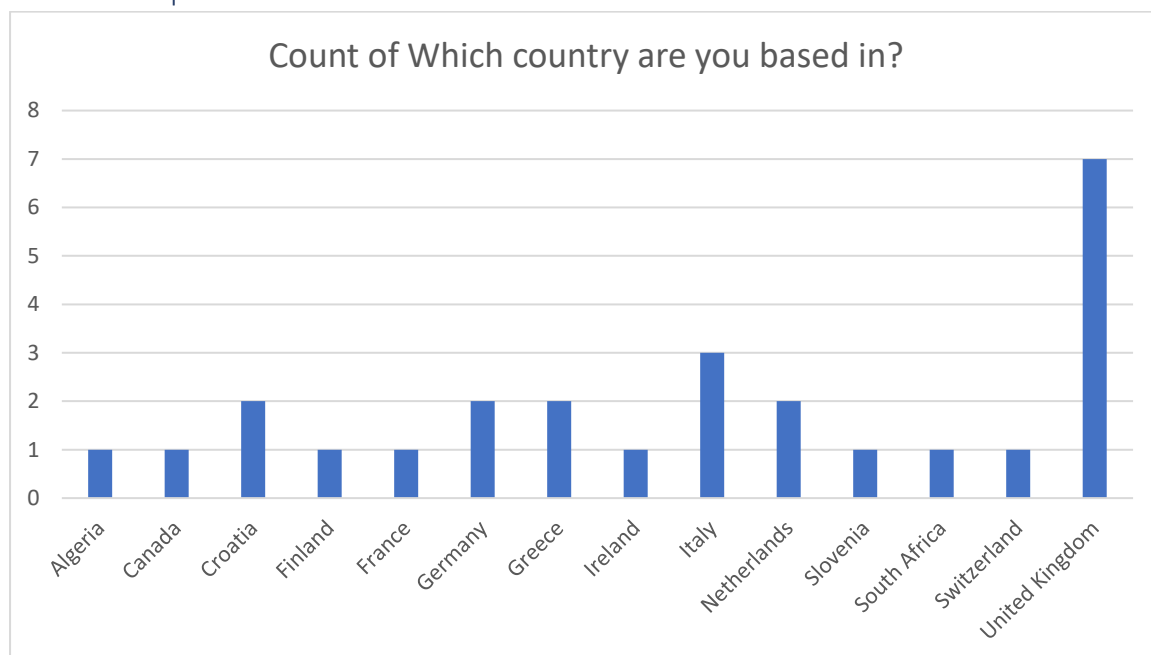
Achieving responsible research conduct requires attention to both **research ethics** (relations between researchers and their ‘subjects/participants/respondents’ – consent, confidentiality, personal data handling, etc.) AND **research integrity** (relations among and between researchers and their impact on the research record and the public – issues of plagiarism, fabrication or falsification of data, inadequate acknowledgment of authorship, inappropriate use of research funds, etc.

1. What are in your opinion the major problems in your research field, in terms of the **ethics** of your work?
2. What works to support ethical research in your field?
3. What does not work?
4. What practical issues/difficulties do researchers face (if any), in your field, when trying to reconcile funding and research ethics?
5. Please specify which resources and ethical guidelines were useful and why

Survey answers

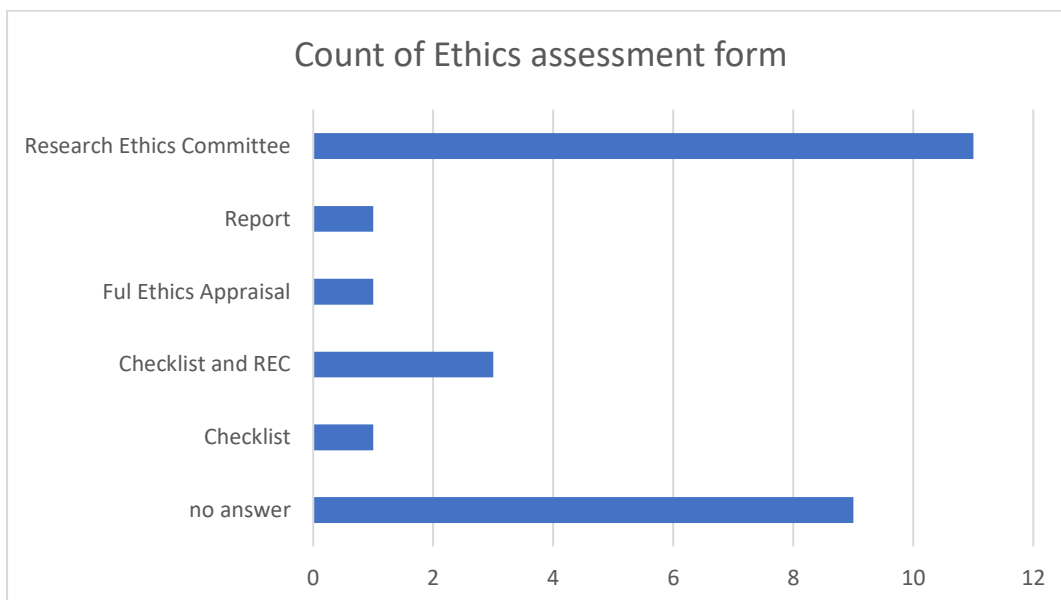
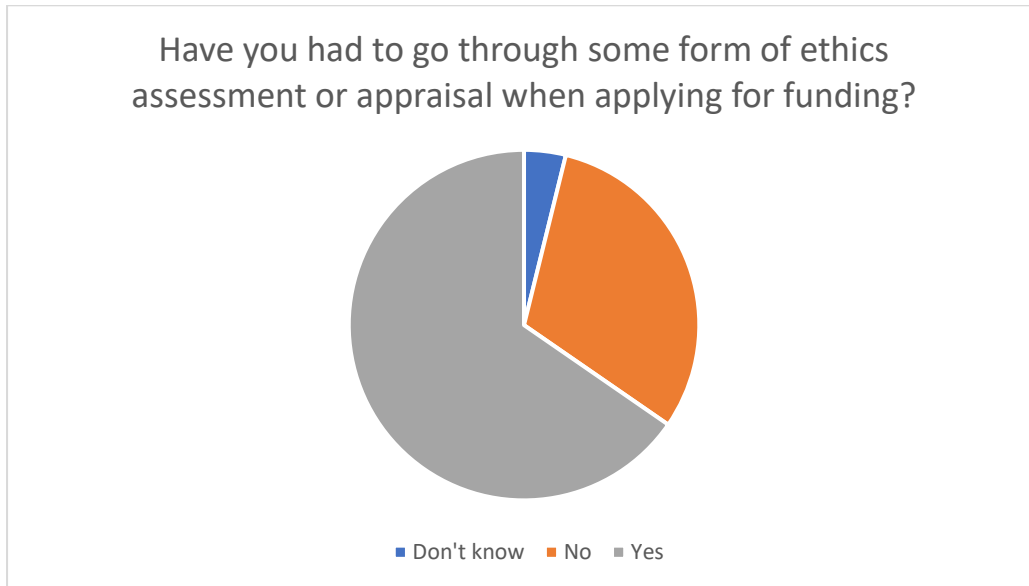
The answers to the survey questions can be seen in the following graphs and tables

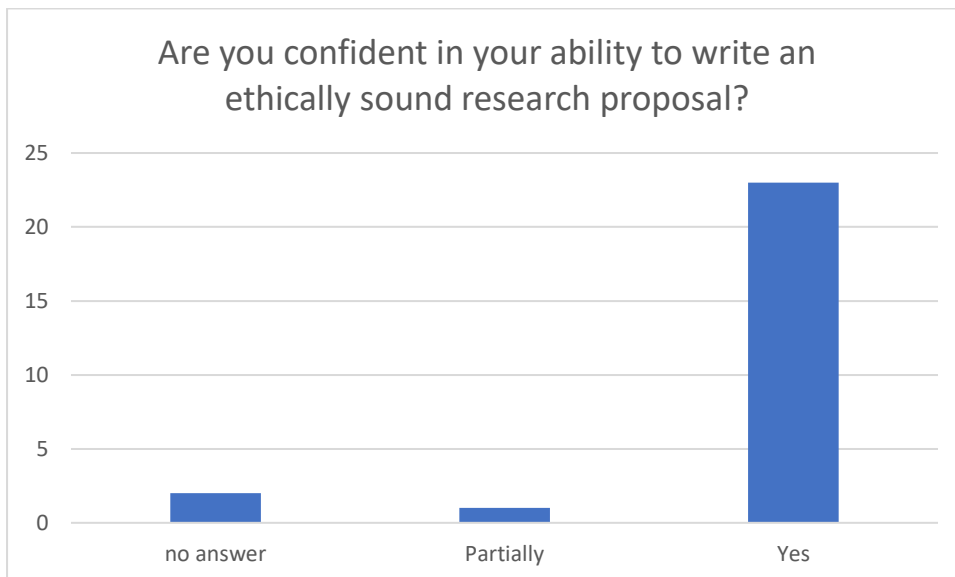
Answers to question set 1



Does your research involve issues that deal with:	Count
Artificial intelligence and robotics	4
Behavioural research collecting data from social media and internet sources	6

Covert research and surveillance	5
Other	8
Working in dangerous areas and conflict zones	3





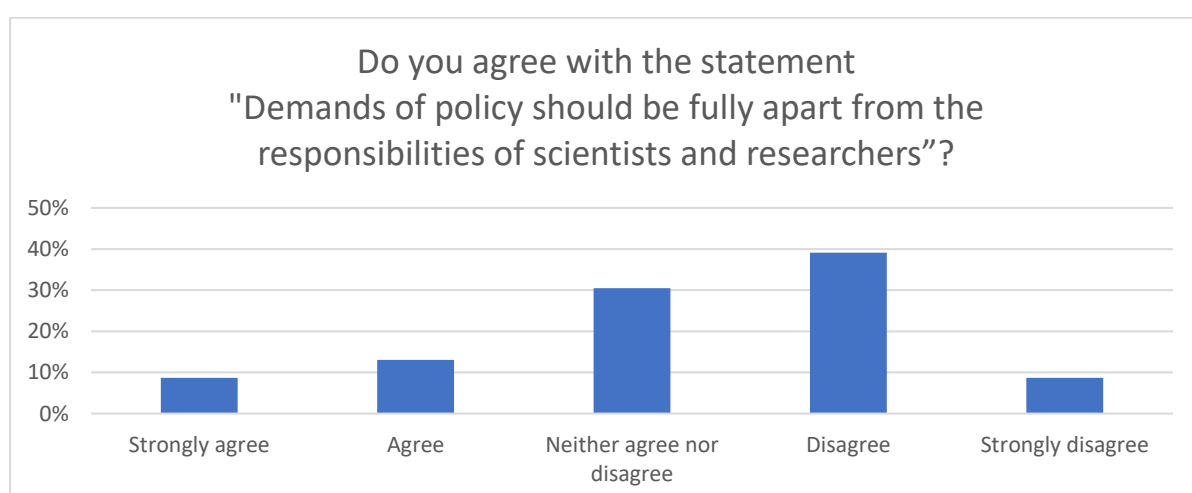
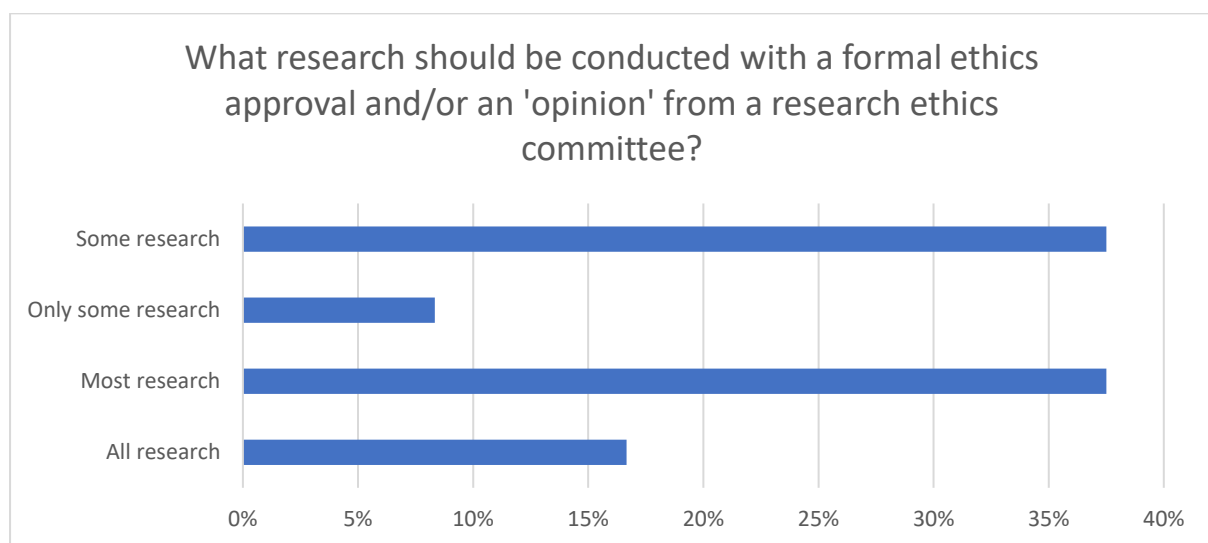
Analysis of the survey participants

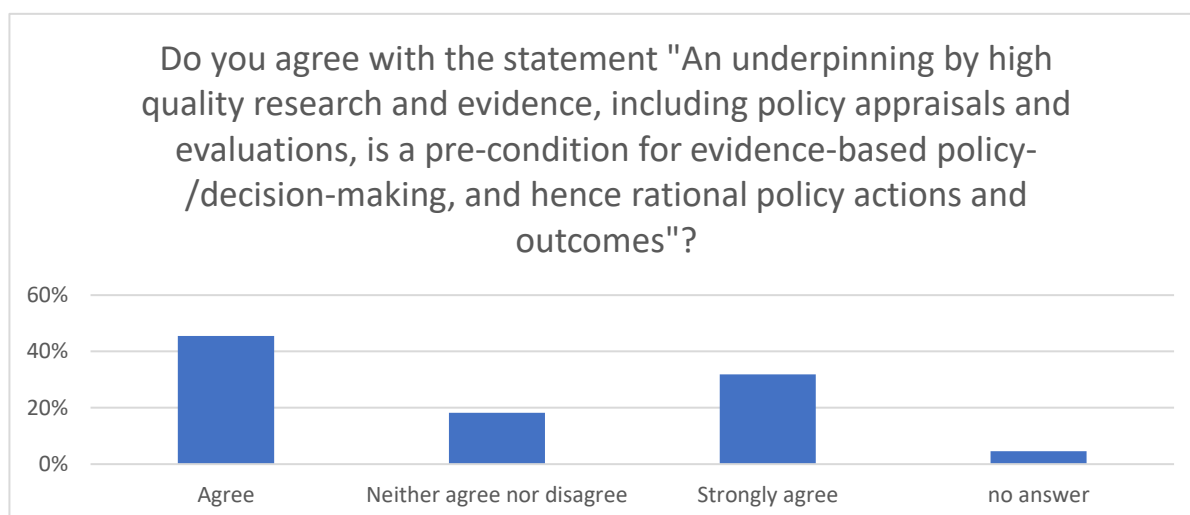
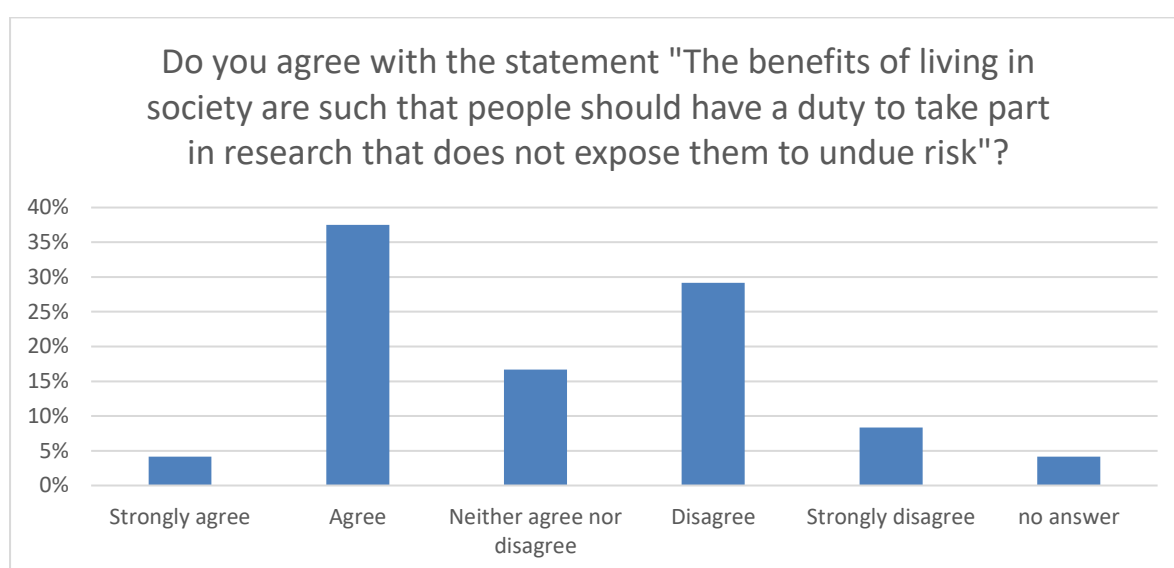
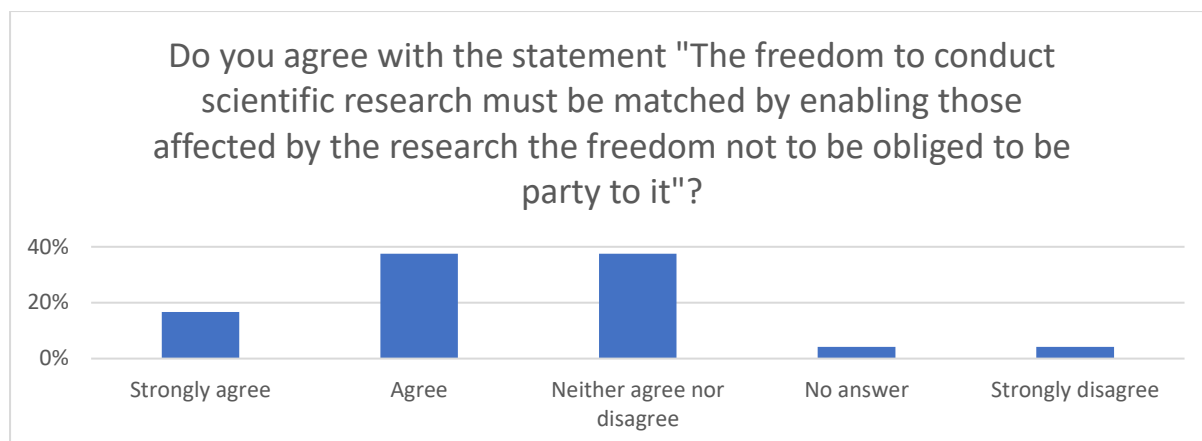
The survey participants tend to be experienced with ethics assessments, which is to be expected as the PRO-RES stakeholder list that was used to create the invitations, was targeted to people with experience in ethics and integrity issues. Most of the participants had to complete ethical assessments regarding their funding sources, and most of them did it by themselves or with the help of colleagues from their organisation.

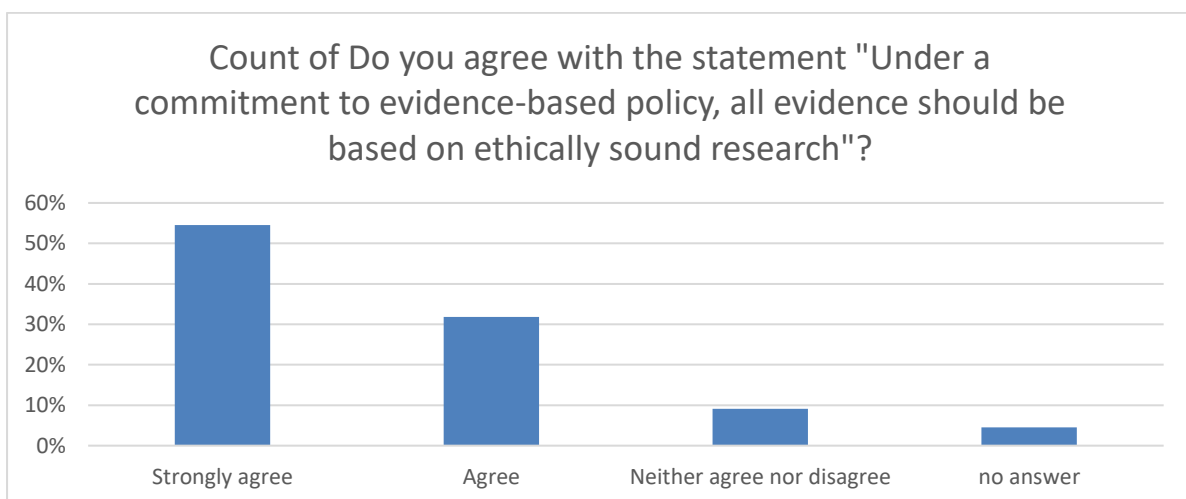
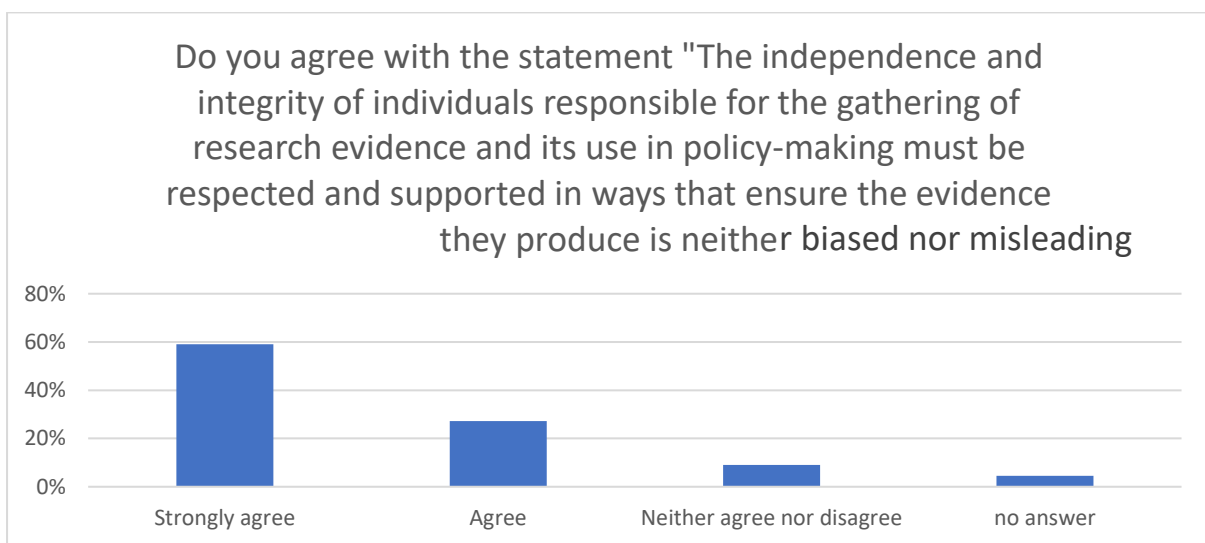
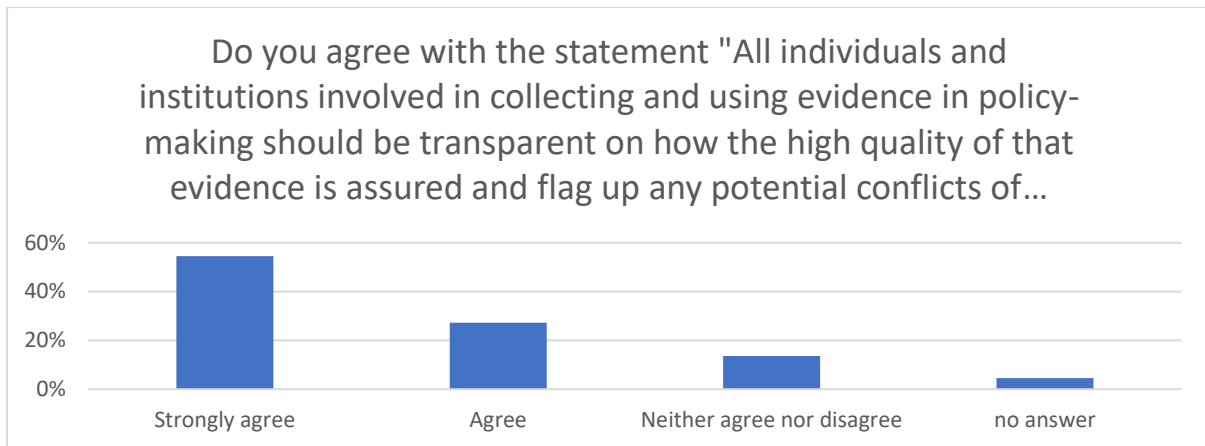
The UK prominence in the survey answers is probably a combination of the prominence of UK based organisation within the stakeholder list, as well as small number statistics.

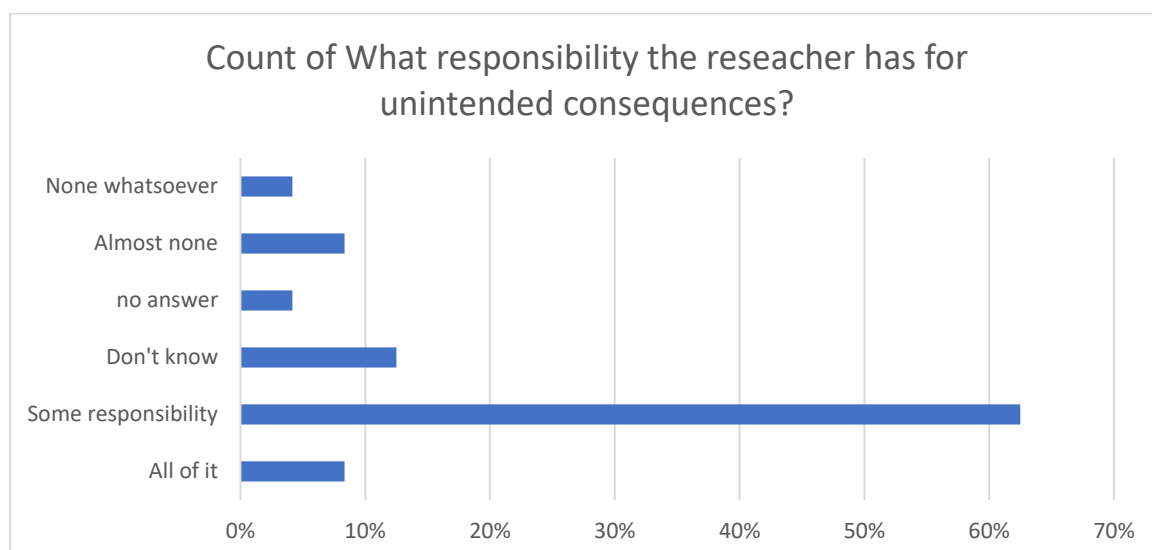
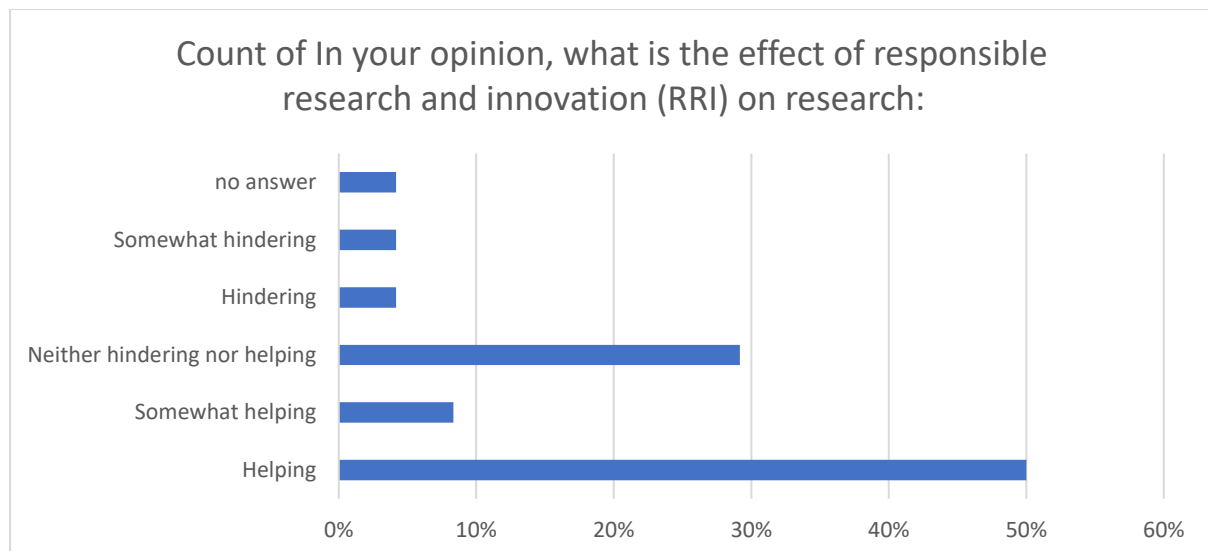
Answers to survey questions regarding the moral responsibility of researchers

The answers to the second set of questions, that deal with ethics in research and the responsibilities of researchers are presented here.









Analysis of questions regarding ethics and the moral responsibility of researchers

Participants agreed that some sort of formal ethics approval should be part of all research. In fact, there was not a “no” answer to question 1. About half of the participants agreed that policy demands are indeed part of the responsibilities of researchers and scientists, with 20% expressing an opposite preference. 30% remained neutral to the statement no 3, not showing a strong preference. This points to an acceptance that science is not apart from society but it is expected to contribute to the social good, as expressed by policy demands (assuming policy represents the will of society of course). This “societal return” from science has been a driving factor in the last decades, in funding research.

Most participants agreed that subject of research also have the freedom to not be part of said research, with a substantial portion remaining neutral in this statement. However, the participants were split on to whether there is an actual duty by society to take part in research. This indicates an appreciation for the rights of research participants.

Unsurprisingly , participants were much an agreement that evidence based policy needs to be underpinning by high quality research and evidence, as well as the need for transparency and independence of researchers.

Participants also agreed that evidence base policy also requires ethically sound research. This correlates well with the answer that the researcher bears some if not all, the responsibility of the unintended consequences, thus emphasizing the need for ethically sound research.

Finally, the participants were either convinced that the concept of RRI was helpful or at least neutral on research.

Overall, the survey participants were in agreement that research should be done ethically, both to safeguard the rights of the research subjects (if applicable) but also to ensure good results if research is to advise policy.

Question set 3: Open ended questions

The last part of the questionnaire included open ended questions, in order to collect diverse input. The following sections provide a summary of the answers.

1. What are in your opinion the major problems in your research field, in terms of the ethics of your work and its scientific integrity?

Major problems that were identified:

- a) The Ethical review process of research was mentioned by most responders, citing bypassing of ethics evaluations, lack of independence of Programme Evaluations, equity and diversity (or lack of) in research and RPOs not taking full responsibility for the consequence of their work. Additionally, the pre-eminence of medical codes and policies and their non-applicability to social research was also cited.
- b) Regarding policy and policy advice, there were also several issues mentioned such as the allocation of research interests to 'safe' areas, the lack of evaluations of previews implemented policies and conflicts between the need for robust and timely research evidence in certain areas and the ability to deliver that in ways that safeguard participants' rights
- c) Quality of research or the way research is conducted, involving long and complicated processes or complex legal requirements. Data protection legislation in particular. The lack of understanding of context and cultural critique prior to developing ethics applications and isolation from wider social responsibilities such as activism was also cited.
- d) Technology and its uncertain impact, regarding the belief that it can solve "everything".
- e) Integrity issues such as plagiarism and data misuse.

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

- a) Open discussion with fellow researchers.
- b) Ethical education of research students.
- c) Lowering of publication pressure
- d) Resources (Money, time but also guides and advisors).
- e) Support of and trust in researchers' professionalism.
- f) Networks and contributions from those conducting the fieldwork in the country where it will take place
- g) Ethics integrated to the project closely and a strong tradition of ethical review.
- h) Being presented with the argument that technology is leaky and legal compliance does not respect reputation.

3. What does not work?

- Closed door policies and/or time pressure to 'approve' research without fully assessing applications. This includes ethics committees that may not be fully familiar with the research

being assessed or isolated committee members. Superficial approach to ethics and lack of evaluations.

- Complex guidelines and regulations that are a hinderance rather than a help.
- To leave ethical issues completely to the researchers.
- Conflicts between the demands of (government) funders and ethical imperatives.
- A course on teaching/learning ethics. Such a course remains only theoretical, not practical.

3. What practical issues/difficulties do researchers face (if any), in your field, when trying to reconcile funding and research ethics?

- Few accept and fight for the need for ethics. There can be tensions between what is proposed in an application and what compromises need to be made when research goes live. Sometimes ethics loses out.
- Regulations ported from other research fields and not workable in another, with the example given of written consent forms when researching illegal immigrants and their children.
- If there is a tension, it may be because funding requirements differ from those required by an ethics committee or ethics framework (probably relatively rare), or commonly, the timelines for the funders are much tighter than an ethics committee is aware of, resulting in last minute scrambles.
- Fairness for vulnerable research communities, which might necessitate actions which are not part of the funding (i.e personal feedback).
- The lack of proper ethical evaluations of the conducted research to which one could refer to.

5. Please specify which resources and ethical guidelines were useful:

- EU GREAT project guidelines, RRI for research governance, particularly the engagement of stakeholders at all levels. AREA framework by McNaughten et al, and EU RRI guidelines.
- BPS guidelines
- THE EUROPEAN CODE OF CONDUCT FOR RESEARCH INTEGRITY, H2020 guidance (https://ec.europa.eu/research/participants/docs/h2020-funding-guide/cross-cutting-issues/ethics_en.htm), TENK Guidelines (<https://www.tenk.fi/en/tenk-guidelines>)
- www.globalcodeofconduct.org/
- The ESRC, GSS, SRA guidelines mentioned, as well as a strong organisational culture
- The UK Social Research Association.
- Guidance produced by the UK health research authority. Despite being health focussed it is broadly relevant.

Codes used

- ACM Codes of Ethics
- British Psychological Society code of ethics
- Code for social science research as adopted by the Dutch universities
- Declaration of Helsinki
- EC Ethics in Social Science and Humanities
- Ethic code for croatian science community
- Framework for Research Ethics (ESRC)
- GDPR (Data management)
- General guidelines regarding research with minors
- Global Code of Conduct for Research in Resource-Poor Settings
- Horizon 2020 Guidance How to complete your ethics self-assessment

- RESPECT code of conduct for socioeconomic research
- Singapore Statement
- SRA
- TCPS (Chapter 10)
- UK concordat to support research integrity
- UK Data Protection Act
- UNICEF Procedure for ethical standards
- WHO GBV guidelines

Conclusions

The online consultation, resulting in deliverable D2.4, was an early attempt to gather the opinion of the larger community. The survey was launched before the mid term conference, however the response was pretty low. There are 2 factors that might have contributed to the low response rate:

a) a general “survey fatigue”. The low response rate has been observed in several other projects and it is a consequence of the number of surveys that experts are requested to fill in quite frequently, as well as the nature of the survey that, by necessity, included open ended questions (and thus not easy to just click through to complete).

b) The survey included several questions on ethics and ethical reviews, which is a subject of interest to people that have to pass through them or design such reviews but not necessarily interesting to others, even if the latter population is concerned with ethics. It is to be noted that the low response rate measurement is also due to participants that simply did not finish the survey which confirms the issue of survey fatigue mentioned above.

Elimination of open-ended questions would certainly have helped to improve results but the subject matter is not easy to capture with simple multiple choice questions.

The PRO-RES interviews, that took place later, were much more representative and in-depth of the wider community and at the end, the lack of a good result on this deliverable, did not jeopardise the input to the project. The process to design the reviews started about 3 months after the survey and thus it was clear that the interviews would provide a much more in-depth view of stakeholder opinion.