



TREASURE

D10.1: H - Requirement No. 1 *Ethical handling of research on humans in TREASURE*

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EXECUTIVE SUMMARY

This document is the first iteration of the state of the art in the ethical practice of research on humans in TREASURE. It was authored by Alberto Cottica (EDGE research director) with support from Matthias Ansorg (EDGE CTO and data protection officer), and approved by our Ethics Advisor, Marco Manca.

It is structured as follows. We first set the stage, singling out TREASURE partners who plan to conduct research on humans. Next, for each of such partners, we lay out the grounding and governance of our ethical stance; enumerate TREASURE's ethical risks related to research on humans as we foresee at the time of writing; and describe the measures we take to counteract those risks. Ethical risks not associated with research on humans and their proposed mitigation strategies are the object of deliverable D10.2 and fall without the scope of this document.



TABLE OF CONTENTS

DISCLAIMER OF WARRANTIES	2
EXECUTIVE SUMMARY	3
1. Which partners plan to conduct research on humans in TREASURE?	5
2. Ethical practices at Edgeryders	5
2.1. Sources and principles.	5
2.2. Ethics advisor.	5
2.3. Approach.	6
2.4. Ethical risks and how we neutralize them.	6
3. Actionables	9
3.1. Consent funnel.	9
3.2. Public forum for the research group.	9
3.3. Social contract.	10
3.4. Data minimalism.	10
Annex 1: a draft TREASURE social contract.....	11
Annex 2: Consent funnel questions and feedback mechanism	12



1. Which partners plan to conduct research on humans in TREASURE?

In July-August 2021, EDGE reached out to all TREASURE partners to inquire about their intentions about research on humans. We produced and circulated a memo, which translated the implications of the consortium's duty to produce deliverables D10.1 and D10.2 into a checklist for each partner. The memo asked participants that planned to do no research on humans to declare so, and warned:

To be clear, “no research” means no research; no workshops, focus groups, surveys, nothing at all.

The circulation of the memo was accompanied by the offer of meetings to answer any remaining questions the partners might have (some partners took us up on the offer). Further, we reached out by e-mail to each individual partner to make sure they were comfortable with making the claim that they would not do any research on humans.

All TREASURE partners, except EDGE, confirmed they would not be doing research on humans. They committed to informing the coordinator and the project officer if they, in the future, considered that some research on humans has become necessary. Records of their statements are kept on the TREASURE online workspace.²

EDGE itself plans to run ethnographic research, whose purpose is to understand how vehicle users and citizens in general understand circular economy practices in the automotive industry. This is done in two ways. The first is running an online forum, where a free-form conversation about this can unfold. The second is organizing 10 physical events. The posts on the forum and the participant observation of the events constitute the raw data of the research. Most of this happens in task 2.3.

2. Ethical practices at Edgeryders

2.1. Sources and principles.

TREASURE's ethical compass is grounded in the European Convention on Human Rights and the EU's Charter of Fundamental Rights. It strives to orient the research activity in ways that will uphold the principles therein, among which: human dignity (“people are not datapoints”); transparency of the research process; informed consent to participation; privacy and data protection; inclusivity; protection of vulnerable individuals; full disclosure of research results.

2.2. Ethics advisor.

Our ethics advisor is Marco Manca, a medical doctor and scientific attaché at CERN in Geneva. Marco is Chairman of the Board and co-founder of SCIMPULSE Foundation, a Dutch public benefit organization dedicated to “breaking through the chains of our economy's incentive scheme on research and collaboration”.³

² <https://edgeryders.eu/t/ethics-in-treasure/16055/16?u=alberto>

³ <http://www.scimpulse.org/about-us/>

2.3. Approach.

TREASURE considers that a project's morality is the set of values underpinning it. Its ethics is the ongoing evaluation of how the actions it takes affect everyone involved in the project, seen through the prism of those values. So, ethics is something you do; it's a style of running a project. Ethical integrity is found, and evaluated, in action.

This is important, because some ethical risks can be forecast *ex ante*, and measures to deal with them can be planned ahead. But human systems are fallible: mistakes might happen (in fact they will always happen in a sufficiently long run). The "ethics as action" approach allows us to shift the focus from trying to forecast every possible contingency to fixing things, together with the project's community and acting with its interest at heart.

In medicine, we find that doctors that are least likely to be accused of unethical behaviour are not those who make the least mistakes, but those who are best at communicating openly the mistakes they do make, explaining how they propose to fix them, and actively listening to what the patients have to say about the situation.⁴

This translates into three principles:

1. Ethics as action: TREASURE considers that its ethical stature is only as good as the actions it undertakes to neutralize the ethical risks our research entails. The accent is on processes, not on values.
2. Openness and response over anticipation. Some risks can and should be anticipated. Others can not. It is important to stay open to acknowledging unanticipated ethical risks, and reacting quickly, in full honesty and transparency, to fix them.
3. Data management has ethical implications, so we treat the two together.

2.4. Ethical risks and how we neutralize them.

- a. Risks of low transparency.
 - i. **Watching over people's shoulders.** Participants in the TREASURE conversations might not be fully aware that researchers are watching, and feel betrayed when their words are used to inform weighty conclusions. The project's online space will explain clearly and in simple language what is going on, how the participants' contributions will be used and so on. To help raise the situational awareness of participants, we deploy a *consent funnel* (see below): people are not allowed to post until they have answered correctly one or two simple questions about what is and is not appropriate to share in TREASURE. Note that, in principle, there is a tradeoff between transparency and full consent on one side, and inclusivity on the other side: navigating the consent funnel risks to come easier to more highly educated, more privileged participants. In this case, we propose that the extra effort demanded of participants is worth the gain in consent quality and transparency. To maintain the project as inclusive as possible, we make every effort to keep the language plain and simple, and we make the text available in multiple languages.

⁴ Kachalia, Allen, et al. "Liability claims and costs before and after implementation of a medical error disclosure program." *Annals of internal medicine* 153.4 (2010): 213-221.

- ii. **Running away with the data.** Once participants have contributed to TREASURE, the text of their contribution is treated according to the methodology described in the GA. This process deploys research methods whose workings are not as explicit to participants as the TREASURE forum itself. To help participants make sense of how their contributions are processed into scientific knowledge, we publish and give wide publicity to the project's data management and data protection processes. Additionally, we publish an outline of our research proposal and all deliverables, as well as an *interactive dashboard for Semantic Social Network Analysis*. With it, participants (as well as other scholars, policy makers and so on) can better follow the thread from individual contribution to overall conclusions.
- b. Risks of low openness.
 - i. **Being locked in the ivory tower.** Despite our best efforts, publishing documents and other artefacts might not be enough to ensure full transparency. Some of those documents might be quite technical, and speak more to fellow scholars than to members of the general public participating in the TREASURE forum. We solve this issue by ensuring real-time access to the research team. This happens via two mechanisms. The first one is community management. A trained online community manager watches over the TREASURE forum; her task is to welcome, facilitate and assist participants. This includes answering any question concerning the research process, and connecting whoever asks with the researcher who can best answer that question. The second mechanism is the research group's public online forum.
 - ii. **Box-ticking mentality.** There is a tendency to treat ethics in research as a list of boxes to tick. To avoid the temptation, we conduct peer reviews with the community on whether we are delivering on the true meaning of our commitment to high standards of morality, transparency, openness and fairness. We do this through offline meetings, and woven into our calendar of project workshops.
- c. Risks of unfairness.
 - i. **Hoard IPR on content.** Researchers tend to get proprietary on "their" data. Here, however, data are utterances by people, who have a right to own (also in a legal sense) their content, and to be recognized for it. We assign the IPR of any contribution to the TREASURE debate to its author. However, said content is published with a Creative Commons license, maintaining the legal integrity of our workflow.
 - ii. **Appropriate the credit for collective work.** WP2 in TREASURE is a crowdsourcing exercise. We will be building research results on the work done by hundreds of community members. There is a risk for all the credit to go to the authors of our research papers, treating the community as inanimate "data" rather than a co-creator. To avoid this risk, we should get creative and find ways to honor the community. For example, we might run scripts that compute the percentage contribution to the discussion of each user, and awards co-author status to the largest contributors.⁵
 - iii. **Vague social contract.** If it is not clear who gets what out of everyone collaborating to TREASURE, we might get a less enthusiastic collaboration, and a suspicion might linger that the scale is turned in favor of the professional

⁵ Some journals might agree to have a co-author named "TREASURE study group" (or "TREASURE study population"), with the printed version being limited to this, and the online version having a way to point to the full list of names that you took input from.

researchers (which, in participatory research, it usually is). To avoid this, we deploy an explicit social contract for the project, also as part of Task T2.3.

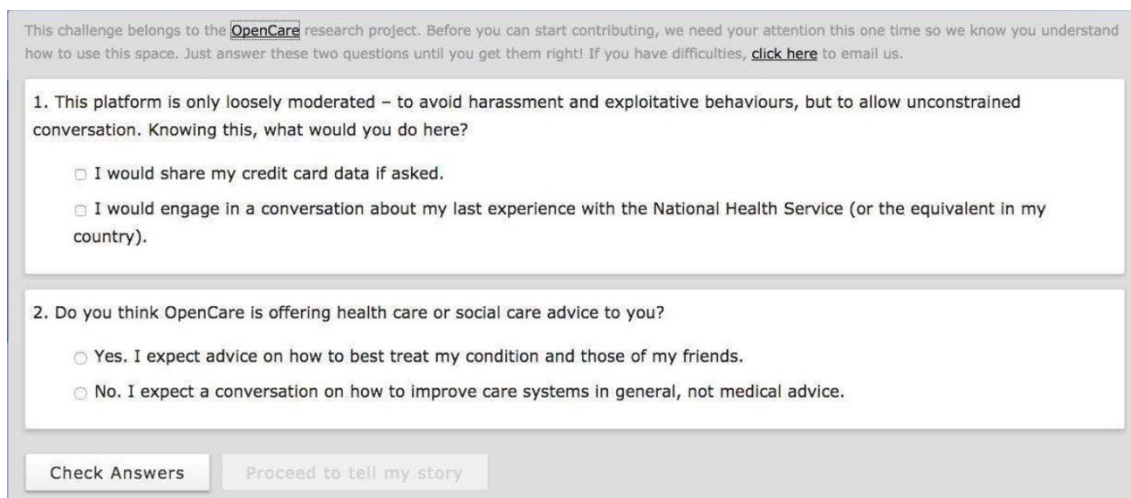
- d. Risks of surveillance/insufficient protection of data
 - i. **Third parties might link participants' political position with their online identities.** Participation in TREASURE generates knowledge about the political position of participants with respect to environmental matters. If linked to their online identity *outside* of TREASURE, this information could enable profiling, targeted advertising and so on. To minimize this risk, we adopt a strategy of *data minimalism*.
- e. Other general risks and mitigation measures
 - i. **Children.** We discourage children from participating in TREASURE, and we do not collect personal data anyway.
 - ii. **Use of previously collected data.** Using data collected previous to TREASURE's starting date poses a consent problem. The people providing those data could not know that they would be used for TREASURE, which did not exist at the time. So, we do not plan to re-use previously collected data. Of course, by "data" in this context we mean "information provided by physical persons on how they perceive issues pertinent to TREASURE".
 - iii. **Data protection impact assessment.** We consider that the conditions that mandate a DPIA do not apply, as TREASURE does not meet the criteria laid out in GDPR for a high-risk project.⁶
 - iv. **Profiling, tracking, surveillance, automated decision-making and big data.** None of these takes place in the TREASURE platform, except in the trivial case of cookies that keep users logged in from one visit to the next using the same device, unless they decide to log out.
 - v. **Security.** All connections to the TREASURE platform are SSL encrypted, and all passwords are stored in a way that does not allow transforming them back into the original text.
 - vi. **Trans-border hosting and transfer of information.** The TREASURE platform is hosted and backed up within the European Union only.
 - vii. **Data protection officer.** The person in charge of data protection at Edgeryders, the partner hosting the TREASURE platform, is Matthias Ansorg. His name, position and email address are indicated in the page of the website dedicated to data protection.

⁶ <https://gdpr.eu/data-protection-impact-assessment-template/>

3. Actionables

3.1. Consent funnel.

A consent funnel is a device to replace the traditional (and ethically ineffective) ‘I accept the Terms and Conditions’ box to tick. It is a gateway to the platform where participants can consent to sharing and handling of their information for the purpose of the project, inspired to the principles of honesty and transparency of the Portable Legal Consent.⁷ The idea is that the platform asks first-time users questions aimed at making sure they understand that they are in a public space for debate and should not reveal personal information unless they are comfortable with it being public. Users are not allowed to post until they get the questions right. An example is shown in Figure 1.



This challenge belongs to the [OpenCare](#) research project. Before you can start contributing, we need your attention this one time so we know you understand how to use this space. Just answer these two questions until you get them right! If you have difficulties, [click here](#) to email us.

1. This platform is only loosely moderated – to avoid harassment and exploitative behaviours, but to allow unconstrained conversation. Knowing this, what would you do here?

I would share my credit card data if asked.

I would engage in a conversation about my last experience with the National Health Service (or the equivalent in my country).

2. Do you think OpenCare is offering health care or social care advice to you?

Yes. I expect advice on how to best treat my condition and those of my friends.

No. I expect a conversation on how to improve care systems in general, not medical advice.

TREASURE’s consent funnel:

- Contains the word “research”, and clearly conveys that the TREASURE forum is meant to collect data for ethnographic research.
- Is available in all the languages of the forum.
- Points to a simple process for opting out of the research in the “success” message.
- Records in the platform’s database the date and time when each participant has given consent.

3.2. Public forum for the research group.

Instead of using email, we (EDGE) run our internal dialogue about the project on the same online platform as the project itself, and we keep this dialogue open on the web, indexed by search engines and so on. Other TREASURE partners are also encouraged to do so. Participants in TREASURE are welcome to read the research forum and contribute to it, asking questions or offering suggestions. We will, of course, also need a non-public group for some activities, but the rule is going to be “if there is no compelling reason for it not to be public, it should be public”.

⁷ <http://sagebase.org/e-consent>

3.3. Social contract.

We propose a TREASURE social contract, to be made available and clearly signposted on the platform. It is loosely based on the social contract for community-provided care produced by a previous Horizon 2020 project called OPENCARE.⁸ It is reported in Annex 1.

3.4. Data minimalism.

TREASURE:

1. Does not enforce a real name policy.
2. Does not require any personal information besides an email address.⁹ Email addresses are necessary to create the account. We do, however, accept one-time email addresses provided by services such as GuerrillaMail¹⁰, and recommend some in our privacy policy page. Email addresses are not visible to users.
3. Never sells data, or disclose them in raw form to third parties.
4. Pseudonymizes our data before publishing them.

⁸ [10.5281/zenodo.1161691](https://zenodo.org/record/1161691)

⁹ <https://edgeryders.eu/terms-of-use-and-privacy-policy/44#chap-6-1> When editing a profile (but not when creating an account), the platform allows (but does not require) the user to enter two further datapoints: a location and a website.

¹⁰ <https://www.guerrillamail.com/>

Annex 1: a draft TREASURE social contract

1. TREASURE, the project you are helping by your participation, is designed to work as a catalyst. It will run until the summer of 2024, though its materials will remain available long after that.
2. We cannot promise you it will solve any of the environmental issues raised by the automotive industry. It is meant for all of us to raise awareness, share with one another information and experiences about how we, as a community, cope with those issues.
3. You are free to use materials from the TREASURE discussion to draw your own conclusions about the issues we discuss. You are free to report those conclusion anywhere, on the web and in real life, subject only to the law and the terms of the license, as long as you attribute those materials to their authors. See here (links to: <https://creativecommons.org/licenses/by/3.0/>) for an explanation of your rights and duties when using these materials. We, the TREASURE research group, plan to do it too. We commit to publicly discussing our practices, to be transparent and to have the opportunity of discovering what could be done better, or differently.
4. TREASURE is funded by the European Commission under the Horizon 2020 framework program for research (grant number 101003587). We commit to procuring and managing resources adhering to the ethical standards we apply in all our activities
5. We have designed TREASURE with you, its community, in mind. We commit to making every effort to maintain its space open for everyone of you to join us and use, or ethically misuse (for example by introducing topics that we did not think connect to the project, but you want to discuss with the community), so that the conversation space we maintain can evolve with the community itself. We are aware we cannot do it alone, and we try to facilitate your participation.
6. We may enforce temporary restrictions to your access to the TREASURE space, under those circumstances in which your behavior represents a risk for others (e.g.: violent or otherwise threatening behaviors).
7. We commit to continuing independent evaluation of our activities, and to turning any breach or near miss consequently identified into the awareness of a changing landscape that would guide an evolution of our operations and governance.

Annex 2: Consent funnel questions and feedback mechanism

The consent funnel asks of participants to answer the following questions, and provides them with the given options to answer. The questions are optimized for all research activity such as described on Edgeryders, not just for TREASURE.

Q1. This platform is used for research (learn more). Researchers are encouraged to treat what we post into it as a window into societal, economic, technological, and political trends and transformations that affect all of us. As you participate in these discussions, you might reveal where you stand with respect to important societal, economic and political issues. Knowing this, which of the following best describes your position? [single choice answers provided as follows:]

1. I do not fear bad consequences when sharing with others my views and alignment on societal, economic, technological and political issues. Outcome: allow posting.
2. I worry about the risks involved in sharing my views and alignment online, where others (such as the government or my employer) could access them. But I will participate in the conversation on this platform under my real name. Outcome: do not allow posting. Feedback: We want you to stay safe. If sharing information about your views and alignment is risky for you, you should consider not participating in public discussion. We would still like to hear from you. You could (1) participate under a pseudonym, or (2) register under a one-time email address to reduce the risks that the content you post will be linked to you. Or (3) you can contact our community managers securely and anonymously to share your content.
3. I worry about the risks involved in sharing my views and alignment online, where others (such as the government or my employer) could access them. Therefore, I protect my identity to a degree I think is adequate, for example posting under a pseudonym, using a fake e-mail address, using a VPN etc.. Outcome: allow posting.
4. I worry about the risks involved in sharing my views and alignment online, where others (such as the government or my employer) could access them, and I don't know how to deal with that risk when posting on this platform. Outcome: do not allow posting. Feedback: As for answer 2 above.

Q2. This platform is only loosely moderated, to avoid harassment and exploitative behaviour, but to allow unconstrained conversation. Knowing this, would you: [multiple choice answers provided as follows:]

1. Share my credit card's details at another participant's request. Outcome: do not allow posting. Feedback: This is a public forum meant for conversation on general issues, and it is not secure to share personal information on. You should not share personal information that you do not want out in the open on it, such as your credit card detail, with anyone (including researchers and community managers and under any circumstance).
2. Engage in a conversation about important issues in my country, and how it should be reflected by the government's policies Outcome: allow posting.

Note: the questions are preceded by a sentence explaining why the consent funnel is there. This sentence also contains a link for participants to ask for help, resolve ambiguities and suggest improvements to the questions themselves.

