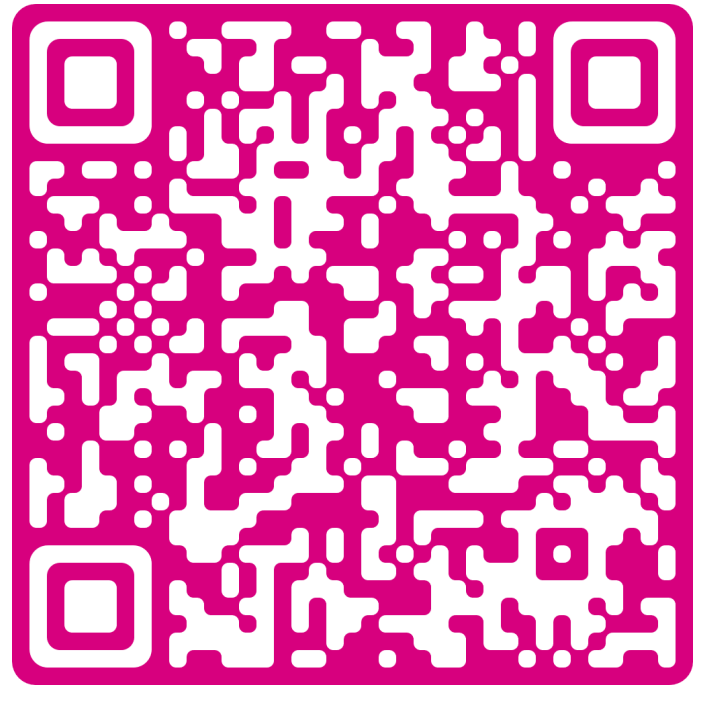


Participatory Real Life Experiments in Research and Innovation Funding Organisations on Ethics

proEthics



The ongoing drive to **open up R&I processes** to participatory practices aims to enhance inclusivity, strengthen effectiveness, provide robust evidence for policy making, and better align R&I with societal needs. However, the engagement of societal groups in such processes can be challenging and bears a series of **ethical risks and requirements**.

One of the most important players in the R&I ecosystem are **Research and Innovation Funding Organisations (RFOs)**. They are responsible for setting research agendas, framing the topics addressed in calls, and as such they co-determine the scope, content, direction, outputs and potential impacts of research. As part of a four-year journey, the PRO-Ethics project sought to **assess the diversity of practices and understandings of RFOs towards the ethics of participation**, and **experiment with new participatory practices in eight RFOs represented in the project consortium**.

As a result of several iterations and learning loops, the main project outcome is the **Ethics Framework and Practical Guidelines** - a comprehensive step-by-step guide for the implementation of ethical participation practices in the activities of RFOs. The Framework seeks to **help organizations to ethically engage stakeholders during all stages of participatory processes – from the preparation and implementation to the evaluation of stakeholder participation**.

THE ETHICS FRAMEWORK AND PRACTICAL GUIDELINES

METHODS

The Ethics Framework was built on insights from existing **literature** as well as **empirical data** collected primarily across **10 pilots** implemented in **two phases**. Four of these pilots were implemented at the beginning of the project and provided experiential inputs to the development of the first draft of the document. In the six pilots of phase II, the draft was extensively tested and improved. The pilots focused on **engaging “non-traditional” stakeholders in the processes of RFOs**, which entails any stakeholder not usually included in such activities. In PRO-Ethics this meant **citizens** in the broadest sense, **residents of an area**, **end-users of a technology**, **people affected by an issue**, **beneficiaries of funding calls**, and **others**. Further feedback was collected from **civil society**, **researchers and especially the citizen science community of practice**, **other RFOs**, **research ethics committees**, **research integrity organizations**, and **other stakeholders interested in preparing, implementing, and evaluating participatory processes**.

POTENTIAL QUESTIONS WE NEED TO ASK WHEN PREPARING AND IMPLEMENTING PARTICIPATORY PROCESSES

- What kinds of processes should stakeholders be involved in and how?
- How do we make sure participants know enough to make decisions?
- How do we choose the right participants and the right processes?
- How can biases be managed and mitigated?
- How do we need to care for participants during their participatory involvement?
- How do we ensure the privacy rights of participants?
- And how can participatory activities be conducted in line with basic principles and values of research ethics and research integrity?

STRUCTURE

The ethics framework consists of **tools and guidelines** that focus on **how stakeholder participation can be ethically organized**. Rather than providing a list of criteria only, the Framework offers a **broad list of questions that should be considered**. Aspiring to address the ethics of participation in the context of R&I funding, the document aims to operate as a **standard for organizing stakeholder participation**, and **how to address ethical issues and risks before and while they arise in participatory processes**. This entails both research ethics in the broadest sense, and the ethics in and of participation more specifically. The framework helps deal with the diversity of views on ethics and participation, the context-specific practices of RFOs, and addresses some important contextual questions:

How is participation justified? What are the goals/outcomes targeted? And what are the underlying ethical issues?

CROSS-CUTTING RISKS IN NEED FOR CONSIDERATION

- definition of appropriate goals for participatory processes
- selection of appropriate participatory methods and type(s) of participant
- choice of appropriate informed consent procedure(s)
- accommodation of (potentially) disadvantaged stakeholder groups
- addressing barriers for participation
- addressing information asymmetries between stakeholders
- safeguarding research integrity in complex transdisciplinary settings
- assessing personal risk factors (physical, psychological, social, etc.)

RELEVANCE TO RESEARCH INTEGRITY

The Ethics Framework is compatible with, and complementary to, other frameworks, standards, and codes of conduct used in the context of R&I. As such, it may also prove **valuable for other organizations that aspire to organize, review or evaluate ethical participatory processes**, such as research performing organizations, research ethics committees and research integrity bodies.

Regarding issues of **research integrity**, the ALLEA Code of Conduct emphasizes the importance of **respect** not only for other researchers, but also research subjects, society, ecosystems, cultural heritage and the environment, as well as **accountability** for wider societal impacts. The Ethics Framework can be a useful starting point for operationalizing these aspirations in research practice.

Moreover, **questions of authorship and integrity of scientific data production** in participatory R&I need to be considered more thoroughly than they have hitherto been, due to the rise of citizen science and other participatory research. In that regard, the PRO-Ethics outputs offer practical examples to the more streamlined items of the Code of Conduct.

Research ethics committees (RECs) could use this framework as a **basis for the improvement of research ethics review**. Ethical review is first and foremost about ensuring the protection of research participants. Many guidelines exist to help RECs assess whether research participants in clinical trials and other research projects are being treated well. However, a challenge is that RECs are limited in their ability to effectively assess the ethical dimensions of community involvement, lay participation and other methods of engagement, as well as the societal, economic and environmental consequences of research. In this regard, the Ethics Framework is a valuable resource. **It provides RECs with important questions and answers to consider with regard to ethics and participation in research projects.**

NEXT DEVELOPMENTS

Connect. Collaborate. Create.

Final conference co-hosted by PRO-Ethics and COESO Project.



19-21 October 2023

PARIS, Aubervilliers
Campus Condorcet

The conference will bring together the diverse European communities that create and support participatory research (funding) and citizen science. We welcome researchers, citizen science practitioners, and supporters from all backgrounds, research funding organisations, ethics and integrity experts, as well as policy makers, to open up a space for networking and mutually exploring citizen science/participatory research initiatives and services. You can [register and share your ideas](#) for how to organise workshops, breakout sessions or other interactive activities. You can also suggest to exhibit your contribution in a more static way, via poster, audio/video, etc

