proEthics

Deliverable

D5.2 PRO-Ethics Framework 1.0

Project	PRO-Ethics – Participatory real life experiments in research and innovation funding organisations on ethics
Project Acronym	PRO-Ethics
Project Number	872441
Deliverable:	D5.2
Submission Date:	30.06.2023
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The framework is currently being developed into a booklet with the help of a graphic designer for better usability. This booklet is expected to be available by September 2023.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

Document Control Sheet

Work Package Number	WP5 (Building forth on WP1)
Work Package Title	Synthesis – Ethics framework and practical guidelines
Task Number	T5.2
Task Title	PRO-Ethics framework 1.0
Deliverable Number	D5.2
Deliverable Title	PRO-Ethics Framework 1.0
File name	D5.2_Ethics_Framework_1.0
Number of pages	21
Dissemination level	Public
Main authors	Martijn Wiarda, Neelke Doorn, Stefanie Schuerz
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Quality Assurance	Alex Glennie, Nyangala Zolho

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

Versioning and Contribution History

Version	Date	Contributor	Notes
_v00	04.02.2021	Giannelos, Reber, Doorn	First draft of Ethics Framework and Guidelines 0.1
_v01	12.02.2021	Reber, Doorn, Glennie, Zolho	Feedback and internal review
_v02	17.02.2021	Giannelos, Reber	Second draft
_v03	04.03.2021	Diependaele	Feedback from the European Commission (EC RTD)
_0.1	**12.03.2021**	**Giannelos, Reber**	**Ethics Framework and Guidelines 0.1 finalization**
_v11	18.07.2022	Wiarda, Doorn	Revision: Feedback from internal RFO survey and 2nd cross-learning workshop
_v12	11.05.2023	Wiarda, Schuerz, Doorn	Revision: Feedback from TAFTIE Workshop, e-consultation, pilot summaries and assessments, general assembly Brussels, activity reports, pilot stories, REC/RIO workshop, stakeholder engagement workshop, 3rd cross-pilot learning workshop, advisory board and external peer reviewers
_v13	30.05.2023	Schuerz	Revision: Reworking of Ethics Framework for usability and accessibility, rewrite of executive summary and introduction, minor revisions of Guidelines
_1.0	**26.06.2023**	**Schuerz, Wiarda, Doorn**	**Ethics Framework and Guidelines 1.0 finalization:** Feedback from final general assembly, advisory board and external peer reviewers
_final	**XX.XX.2023**	**Schuerz, Wiarda, SciAd**	**Final text and layout**

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List of Abbreviations

EC European Commission

R&I Research and Innovation

RFO Research Funding Organisation

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What is this framework and who is it for?

The following framework supports the ethical preparation, implementation, and evaluation of participatory processes in research funding and (applied) research & innovation (R&I). It helps the user understand the context in which they undertake a participatory process and guides them through mapping and addressing the ethical challenges and limitations that might arise. The framework was developed with a focus on the activities of research funding organizations (RFOs), including participation in strategy development and agenda setting, call topic definition and formulation, (project and proposal) evaluation processes, and R&I projects. It thus addresses different contexts, resources, and needs that impact decisions on how to conduct participatory processes in an ethical manner, and provides guidance to ensure stakeholder participation is executed without disregarding values such as fairness, transparency, equality, and privacy. Through this, it might also support future ethics review and evaluation procedures that assess the planning and implementation of participatory processes and offer a common frame of reference for different stakeholders to discuss and understand participation in R&I.

Why ethical participation in the processes of research funding organizations?

There is currently a significant push to open up R&I processes to wider audiences to achieve several aims, including: promoting inclusion, raising the effectiveness, validity and applicability of (scientific) interventions, creating a better and/or wider evidence-base for policy and decision making, and to more closely align the processes of R&I with societal needs. This should in turn allow R&I to better address highly complex, uncertain, and contested societal challenges that are dependent on collaborations between science, technology, society, and policy.[1] The main target group of our framework (i.e., RFOs) plays a crucial role in R&I systems. RFOs operate on all scales – on a regional, national, international and global level – and are responsible for setting research agendas and framing the topics addressed in calls. They also (co-)determine the scope, content, direction, outputs and potential impacts of research.[2]

However, the engagement of societal groups in the processes of RFOs, and R&I in a broader sense, can be challenging. Potential questions we need to ask when preparing and implementing such processes include: 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?

The aim of the ethics framework is to ensure participatory processes are meaningful for participants and organizations; to inspire and guide the preparation, implementation, and evaluation of ethical

[1] See for instance how participatory research practices are being actively supported by the European Commission (EC) through their inclusion in the various funding instruments of Horizon Europe, including the clusters and missions, to address "wicked problems".

[2] The Horizon-funded *PSF MLE on Citizen Science Initiatives – Policy and Practice* pointed out the importance of dedicated funding as an instrument for enabling citizen science and engagement more broadly. See: European Commission, Directorate-General for Research and Innovation, 2023. Mutual learning exercise on citizen science initiatives: policy and practice. Fourth Thematic Report: Enabling environments and sustaining citizen science. Publications Office of the European Union. https://data.europa.eu/doi/10.2777/305248

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participatory processes; and to increase the support for stakeholder participation in R&I. As such, it is a tool for safeguarding the effectiveness, ethics, and justification of stakeholder participation.

How were the Ethics Framework and Guidelines developed?

This document is the main result of a four-year EU-funded project called PRO-Ethics. Its contents were developed through an iterative process and build 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 framework and guidelines. In the six pilots of phase II, this draft framework 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, research funding organizations, research ethics committees, research integrity organizations, and other stakeholders interested in preparing, implementing, and evaluating participatory processes. This feedback was obtained through numerous surveys, workshops, and co-creation efforts, and has led to the final document at hand.

About PRO-Ethics

PRO-Ethics was a four-year Horizon 2020 project running from 2020 through 2023. Its goal was to create and test an ethics framework that includes guidelines and best practices to help organizations engage stakeholders while respecting ethical principles of fairness, transparency, equality, privacy, and sustainability. PRO-Ethics employed an iterative process with learning loops between eight participating RFOs, five expert partners and two international organizations. While PRO-Ethics had a Pan-European outlook, it incorporated and compared local conditions and other specific and cultural characteristics of the partnering RFOs from Austria, the Czech Republic, Germany, Lithuania, Norway, Romania, Spain, and the Brussels Capital Region, which implemented the PRO-Ethics pilots.

The consortium was made up of ZSI (project coordinator), DBT, TUDelft, Sciences Po, Nesta, Eureka, EUREC Office, Innoviris, RCN, CDTI, FFG, VDI/VDE-IT, UEFISCDI and RCL. TA CR was initially a part of the consortium but had to discontinue its involvement after two years. LBG OIS Center was subsequently involved in the project through funding distributed via an open call.

Acknowledgements

This framework and guidelines were developed with valuable input from project partners CDTI, FFG, Innoviris, RCN, RCL, TA CR, UEFISCDI, VDI/VDE-IT, and associated partner LBG OIS Center. These organizations implemented pilot projects from which evidence was drawn and in which the framework and guidelines were tested and refined in an iterative manner.

Similarly, numerous experts in various fields, including citizen science practitioners, representatives from research ethics committees and research integrity organizations, and other research funding organizations outside our consortium participated in our interactive workshops formats to give feedback and find gaps and potential areas of use for the framework. The members of our Advisory Board are of special note here: Margaret Gold, Krista Varantola, Angela Wroblewski and Sanna-Kaisa Spoof supported the pilot processes and reviewed the framework and guidelines at various stages of

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the process. We would also like to thank the many stakeholders, including citizens, end-users, and project beneficiaries, who took part as participants in our pilots and gave important feedback on the various processes.

The design for this report was created by SciAd.

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1 Introduction

As participatory engagement practices are increasingly recognized as a valid and often necessary dimension for research funding organizations (RFOs) and R&I systems more broadly, the need to establish strong ethical parameters and guidance for the implementation of such processes becomes ever more pressing. As the work in PRO-Ethics has shown, established ethics review procedures are often unable to grasp the complexity of participatory processes, while the focus on compliance with existing legal and ethical regulatory frameworks fails to address the nuances and tensions of evolving multi-stakeholder processes.[3] As a result, decades of participatory research (e.g., Technology Assessment) have emphasized **the contextual nature of answers to questions as to why, how, and in view of what quality participatory processes are undertaken.**

The ethics framework consists of tools and guidelines that focus on how stakeholder participation can be ethically organized. Aspiring to address the ethics of participation in the context of R&I funding, this 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?

The four-year work undertaken in the PRO-Ethics project revealed a **diversity of practices and understandings among actors** in how to approach the ethics of participation. **This ethics framework tries to bring together these different approaches into a comprehensive step-by-step guide for ethical participation in the activities of RFOs. As such, it may also prove valuable for other organizations that aspire to organize ethical participatory processes, such as research performing organizations, research ethics committees and research integrity bodies**. It provides questions and steps that cover all stages of participatory processes – from the preparation and implementation to the evaluation of stakeholder participation. It responds to different contexts of implementation, providing key topics and questions to be considered. The ethics framework is furthermore compatible with, and complementary to, other frameworks, standards, and codes of conduct used in the context of R&I.

This document consists of two parts:

- a general description (theoretical introduction) explaining the context of use, scope, objectives, and positioning of this ethics framework, and how it should be applied. This part also includes various experiences of RFOs using the ethics framework;

- tools, guidelines, and a glossary, of which the latter presents taxonomies and definitions. The tools and guidelines offer "actions" to be considered for ethical stakeholder participation. **These should be considered before, during, and after the implementation of participatory processes**. Although the tools and guidelines are written for RFOs, they may be relevant for a broader audience within R&I.

[3] For an in-depth discussion on this issue, see Giannelos, K., Reber, B., Doorn, N., Hövel, P., Lanzerath, D., Tambornino, L., 2021. PRO-Ethics D1.2 Paper Manuscript on Participatory Practices and Ethics Issues in Innovation. Zenodo. https://doi.org/10.5281/zenodo.7980377

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2 Part I: General Considerations

2.1 On Ethics

2.1.1 General considerations on ethics

There is broad consensus that R&I has a substantial impact on society. Innovations are not value-neutral but rather impose certain values, worldviews, and risks on society. By way of illustration, let us consider the possible implications of Artificial Intelligence (AI). AI is often associated with positive impacts such as the automation and optimization of tasks like fraud detection, quality control, and medical screenings. However, algorithmic decision-making also entails certain risks such as biases and discrimination, data misuse, and shifting job markets. These risks are subject to heated debates and show that ethical considerations are needed to ensure that R&I processes result in socially desirable and ethically acceptable outcomes.[4] This is especially urgent for ex-post ethical guidance for innovations already developed and embedded in society.

Ever more researchers urge for early anticipatory and reflective deliberations that help collectively shape innovations when this is still possible[5] (see textbox below with examples of research trends that support participation). A substantial part of this support comes from research fields like Responsible (Research and) Innovation, Open Science, Transdisciplinary Research, Technology Assessment, Citizen Science, and Ethical and Legal Aspects/Implications Research. One of their commonalities is their support for 'upstream' stakeholder participation already in the phases of research funding. Discussing ethical considerations through such participatory processes is one means to cope with the complexity, uncertainty, and contestation associated with (disruptive and/or controversial) R&I. Ethics cannot solely be reduced to standard procedures and legislation only (soft law, ethical compliance), but is a discipline (from applied ethics to meta-ethics[6]) that extends the existing regulatory schemes governing the processes of R&I: **ethics helps decipher legitimacy, tensions, and adequacy of processes and legal compliance while being mindful of contextual specificities**.

Open Science
"Open science is a set of principles and practices that aim to make scientific research from all fields accessible to everyone for the benefits of scientists and society as a whole. […] Open science has the

[4] Still, it must be noted that soft governance of algorithmic systems through ethics – even if formalized and ostensibly regulated – is often insufficient, and sometimes even employed strategically to distract both legislators and society from more fundamental issues when it comes to the intersection of societal, commercial, academic, and political interests. For data justice as a valuable tool for approaching data and AI governance, see: Solano, J.L., Martin, A., de Souza, S., Taylor, L., 2022. Governing data and artificial intelligence for all: Models for sustainable and just data governance. European Parliament. Directorate General for Parliamentary Research Services. Brussels. https://www.doi.org/10.2861/915401

[5] Van den Hoven, J., 2014. Responsible Innovation: A New Look at Technology and Ethics. In M. J. Van den Hoven, N. Doorn, T. Swierstra, B. Koops & H. Romijn (Eds.), Responsible Innovation 1: Innovative Solutions for Global Issues. Dordrecht: Springer, pp. 4-7.

[6] Reber, B., 2016. Precautionary Principle, Pluralism and Deliberation: Science and Ethics. London/New York: ISTE/John Wiley & Sons.

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potential of making the scientific process more transparent, inclusive and democratic." United Nations Educational, Scientific and Cultural Organization (UNESCO)[7]
Citizen Science
"Citizen science is an 'umbrella' term that describes a variety of ways in which the public participate in science. The main characteristics are that: (1) citizens are actively involved in research, in partnership or collaboration with scientists or professionals; and (2) there is a genuine outcome, such as new scientific knowledge, conservation action or policy change." European Citizen Science Association (ECSA)[8]
Transdisciplinary Research
"Transdisciplinary research […] is a mode of research that integrates both academic researchers from unrelated disciplines – including natural sciences and SSH - and non-academic participants to achieve a common goal, involving the creation of new knowledge and theory. In drawing on the breadth of science and non-scientific knowledge domains such as local and traditional knowledge, and cultural norms and values, it aims to supplement and transform scientific insights for the good of society. It criss-crosses the traditionally separated realms of science and practice and advances both simultaneously." (OECD)[9]
Responsible Research & Innovation
"Responsible Research and Innovation is a transparent, interactive process by which societal actors and innovators become mutually responsive to each other with a view to the (ethical) acceptability, sustainability and societal desirability of the innovation process and its marketable products (in order to allow a proper embedding of scientific and technological advances in our society)." (René von Schomberg, 2011)[10]

[7] From the UNESCO website: https://www.unesco.org/en/open-science/about (accessed 26.05.2023) Read the Recommendations here: UNESCO, 2021. UNESCO Recommendation on Open Science. United Nations Educational, Scientific and Cultural Organization. https://doi.org/10.5281/zenodo.5834767

[8] From the ECSA website: https://www.ecsa.ngo/ (accessed 26.05.2023) Read ECSA's 10 Principles of Citizen Science here: ECSA (European Citizen Science Association), 2015. Ten Principles of Citizen Science. https://doi.org/10.17605/OSF.IO/XPR2N

[9] OECD, 2020. Addressing societal challenges using transdisciplinary research. OECD Science, Technology and Industry Policy Papers. No. 88, p. 9. OECD Publishing. Paris. https://doi.org/10.1787/0ca0ca45-en

[10] Von Schomberg, R., 2012. Prospects for Technology Assessment in a framework of responsible research and innovation. Technikfolgen abschätzen lehren: Bildungspotenziale transdisziplinärer Methode, pp. 39-61. Wiesbaden: Springer VS. For more information and practical support in the application of ethics in RRI, visit https://rri-tools.eu/ethics (accessed 26.05.2023).

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The multitude **of ethical theories** suggests that there are several ways in which ethics can be considered in R&I. For instance, ethics can focus on particular types of entities (i.e. action, person, institution, technology); normative factors (i.e., values, consequences, virtues or norms); and foundational normative theories (ways to select normative factors and types of entities). Conflicting factors or hybrid forms of reasoning call for a move beyond regulations (as in ethics reviews/assessments), and to embrace a broader pluralistic scope. These views demand enhanced reflexivity and responsibility.

2.1.2 Ethical assessment procedures and the ethics review

Ethical compliance and appraisals such as ethics reviews in research funding tend to stay close to legal standards and regulations and in turn do not comprehensively cover intricate ethical conundrums as they arise during complex R&I processes – especially if they are structured as participatory processes. Publicly funded R&I is associated with forms of ethics assessment procedures, safeguarding the compliance of (to be funded) research with ethical principles. However, ethics reviews differ across countries and institutions, and ethical procedures are not systematically implemented in funding programs. **The connection between ethical reviews and participation remains underdeveloped, as their link is often unspecified.**

Ethical reviews require skills and knowledge that researchers and innovators frequently lack. Ethical analyses require the identification of ethical aspects; familiarity and conformity with standards; and an understanding of approaches to build, recognize, and justify ethical dilemmas in light of conflicting values. The notions of "right" and "wrong" are based on moral values (ideals), principles and norms that define standards – identified as "ethical principles", some concerning individual rights, benefits, harms, fairness principles, and virtues.

Identifying possible ethical issues provides guidance for R&I and helps reflect on its implications. It may also enhance the transparency and accountability of decision-makers and could lead to better processes. As such, **ethical considerations help address the complexity, uncertainty, and contestation associated with R&I, making these processes more responsible**. Because it is impossible for one single stakeholder group to have a comprehensive understanding of societal risks and uncertainties, identifying and weighing ethical considerations can be supported by involving a more diverse set of stakeholders[11]. These complementary perspectives allow for a more thorough grasp of both the risks and potential benefits associated with complex R&I processes, anchored in the lived experiences of affected individuals[12]. Thus, all dimensions of research and innovation, including research funding processes, could benefit from stakeholder participation.

2.2 On Participation

2.2.1 General considerations on participatory practices

This ethics framework is aligned with the European Commission's strategy on research and innovation, which aims to strengthen "a common ownership of research and innovation policy and promoting the

[11] Stilgoe, J., Owen, R., Macnaghten, P., 2013. Developing a framework for responsible innovation. Res. Policy 42, pp.1568–1580. https://doi.org/10.1016/j.respol.2013.05.008

[12] Harremoës, P., Gee, D., MacGarvin, M., Stirling, A., Keys, J., Wynne, B., Guedes Vaz, S., 2001. Late lessons from early warnings: the precautionary principle 1896-2000, Environment issue report. Copenhagen, Denmark. https://doi.org/10.4324/9781315071985-14

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common research and innovation values" through the co-design and co-creation of R&I activities[13,14]. Participation is a crucial part of various movements such as Responsible Research & Innovation[15] and Technology Assessment[16]. While there is no uniform definition of participation, participation is frequently described as a form of engagement that allows (potentially) affected stakeholders to partake in decision-making for R&I[17]. Following the many theoretical approaches building on Arnstein's ladder of participation[18], truly participatory practices are arguably different from other engagement practices in the sense that they empower stakeholders to varying degrees to shape decisions in accordance with their own values and worldviews. In this, there is a trade-off between the possible control exercisable by researchers, funders, policymakers, and so on, and the level of empowerment experienced by other stakeholders. Participatory practices are furthermore distinct from many engagement forms in that they require forms of two-way communication between the participant and decision-maker[19]. This points towards the many decisions to be made when structuring and implementing a participatory process, all of which come with ethical implications in need of being addressed.

There are numerous supporting and opposing arguments for participation[20]. As discussed in our overview on ethics, participation is needed to identify and weigh ethical considerations to arrive at more socially desirable and ethical outcomes. Participation is furthermore supported by the assumption that tackling complex public problems requires collective decision-making to foster more effective outcomes[21] (substantive rationale). What is more, participation is often argued to enhance the trust in, and the legitimacy of, R&I. Stakeholder participation may also lead to an increased support and adoption of outcomes (instrumental rationale). From a democratic perspective, participation may moreover be considered 'the right thing to do' as potentially affected stakeholders can influence how their lives are being shaped (normative rationale). Yet, participation is not always deemed desirable and is often opposed by those who consider that scientific work is already exposed to many constraints both internally and externally (e.g. international competitiveness).

The connection of participation with ethics has several layers of complexity and ambiguity as there are different (understandings of) approaches, relationships with decision-making, and types of participants

[13] DGRI, 2020. Strategic Plan 2020-2024, p. 4. https://commission.europa.eu/system/files/2020-11/rtd_sp_2020_2024_en.pdf

[14] On the necessity and pitfalls of better aligning research policy and ethical and societal values, see: Novitzky, P., Bernstein, M.J., Blok, V., Braun, R., Chan, T.T., Lamers, W., Loeber, A., Meijer, I., Lindner, R., Griessler, E., 2020. Improve alignment of research policy and societal values. Science 369, pp. 39–41. https://doi.org/10.1126/science.abb3415

[15] Von Schomberg, R., 2013. A Vision of Responsible Research and Innovation, Responsible Innovation: Managing the Responsible Emergence of Science and Innovation in Society. https://doi.org/10.1002/9781118551424.ch3

[16] Grunwald, A., Achternbosch, M., 2013. Technology Assessment and Approaches to Early Engagement, in: Doorn, N., Schuurbiers, D., Van de Poel, I., Gorman, M.E. (Eds.), Early Engagement and New Technologies: Opening up the Laboratory. Springer, pp. 15–34.

[17] Wiarda, M., Sobota, V.C.M., Janssen, M.J., Kaa, G. Van De, Yaghmaei, E., Doorn, N., 2023. Public participation in mission-oriented innovation projects. Technol. Forecast. Soc. Chang. 191, 122538. https://doi.org/10.1016/j.techfore.2023.122538

[18] Arnstein, S.R., 1969. A Ladder Of Citizen Participation. J. Am. Inst. Plann. 35, pp. 216–224.

[19] Rowe, G., Frewer, L.J., 2000. Public participation methods: A framework for evaluation. Sci. Technol. Hum. Values 25, 3–29. https://doi.org/10.1177/016224390002500101

[20] Stirling, A., 2008. "Opening up" and "closing down": Power, participation, and pluralism in the social appraisal of technology. Science, Technology and Human Values 33, pp. 262–294. https://doi.org/10.1177/0162243907311265

[21] Fung, A., 2008. Democratizing the Policy Process. In R. E. Goodin, et al. (Eds), The Oxford Handbook of Public Policy, Oxford: Oxford University Press, pp. 681-682.

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depending on the concrete participatory process. Possible approaches may include participatory evaluation, citizen juries, consensus conferences, deliberative opinion polls, citizen advisory committees, and many more. The role of participation in decision-making may also differ as this may be aimed at consensus, compromises, or disagreement.

Another key issue to address when implementing participatory processes is who exactly should be engaged. Participatory processes are increasingly targeted at "citizens" or "stakeholders", which are not synonymous, nor covering the whole array of potential participants. In any case, it is important to be aware that the terminology chosen for prospective participants has consequences for who might be included and excluded. Thus, the choice and usage of specific terms should be critically reflected upon.[22] For instance, citizen also has a legal meaning tied to nationality which might not be intended when employing the term in a participatory process.[23] Participants can be of various kinds, extending beyond the traditional expert (scientist or researcher) and including for example people with lay expertise and civil society representatives. Other categories that are essential to consider both when defining a stakeholder group and when engaging a specific group of participants include gender, dis/ability, socio-economic background, age, geographic location, ethnicity, and so on. It depends on the exact context which participants are considered relevant.

In light of the various definitions, rationales, approaches, roles, and participants, **a taxonomy as presented in this ethics framework is part of the guidelines and is meant to be used as a common reference point for our working definitions**.

PRO-Ethics identified several needs of RFOs employing participatory approaches. These relate to the definitions of participation and ethics in R&I; ethical dimensions and potential issues; ethical risks and their mitigation; the need for checklists specifying what to consider when involving participants; and considerations regarding ethical challenges, (structural) biases, and points of attention. Furthermore, specific issues have been identified in conflicting interests, methods, and types of knowledge. Subsequently, participation should be understood by means of a case-by-case approach, asking adequate questions, and considering different contextual options.

The perceived benefits and legitimacy of participatory processes differ among stakeholders. There are various characteristics that play a role in participation such as: the means and needs of RFOs, the modes of participation; and the ethical challenges and issues of participation critical to RFOs (identification and representation of participants, avoidance of biases, use of personal data, etc.). All aforementioned insights were used to develop the tools and guidelines in this ethics framework.

2.3 Experiences with the Ethics Framework

In the context of the PRO-Ethics project, nine RFOs experimented with this ethics framework for their stakeholder participation processes. **Collective reflections on the ethics framework's use revealed challenges and potential solutions that may prove valuable for future participatory processes.** These 'lessons learned' related to the recruitment of participants; managing commitment and expectations;

[22] See e.g. Eitzel, M., Cappadonna, J., Santos-Lang, C., Duerr, R.E., Virapongse, A. West, S.E., … Jiang, Q., 2017. Citizen Science Terminology Matters: Exploring Key Terms. Citizen Science: Theory and Practice. pp. 1-20. https://doi.org/10.5334/cstp.96

[23] In this document, we use "stakeholder" as an umbrella term covering everyone who might be affected by, or might affect an R&I process. Due to the focus of PRO-Ethics, our perspective is framed by the endeavor to ethically engage "non-traditional" stakeholders.

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fostering of dialogue and equal participation; accommodation of vulnerable groups; creation of funding themes with participants; lack of expertise in participatory ethics; and planning, flexibility, and resources.

RFOs indicated difficulties in relation to the **recruitment of participants**. While they generally aimed for heterogeneous groups of participants that embody the appropriate representation of stakeholders, it remained difficult to determine what stakeholder representation was appropriate. In piloting participatory processes, the project's RFO partners selected stakeholders on various aspects such as their socio-economic background, education, age, religion, ethnicity, and gender (identity). This in turn posed challenges when considering the intersectionality of participants; a participant may identify with multiple stakeholder groups. A possible way forward is to allow stakeholders to self-categorize according to their own understanding of their identity. In addition, what constitutes 'correct' representation tends to be understood differently among stakeholders. The context-dependent nature of participatory processes provides that such challenges cannot be addressed in a standardized manner. However, RFOs can consider whether representation that 'accurately' reflects society is desirable, given that the politics among participants will then likely reflect the dynamics found in society. It may, for instance, be desirable in some cases to give minorities a stronger voice to mitigate power imbalances. RFOs furthermore wrestled with the recruitment of the targeted stakeholders as these were not always willing to participate. In practice, there is often a tension between which stakeholders should be involved (in terms of desired representation), and which can be involved (in terms of willingness, capacity, resources, recruitment efforts, etc.). Not every stakeholder that is potentially affected by R&I is interested in participation. The RFO partners therefore relied on feasible solutions such as snowball sampling and using multiplier organizations to recruit participants, while acknowledging the drawbacks of such methods (e.g. selection bias). Employing the support of experienced recruiters may also help address some of the above-mentioned challenges.

Managing commitment and expectations posed challenges as stakeholders have different views on R&I, RFOs, and concrete participatory processes. Experiments suggest it is important to understand, and to accommodate, the needs of participants. Some stakeholders may require different forms of participation or may need financial compensation. It proved helpful to transparently communicate everyone's expectations regarding the roles, scope, purpose, process, and outcomes of the participatory activity. Such aspects can, for instance, be made explicit in a code of conduct.

Various difficulties emerged during the participation process in relation to organizing **meaningful dialogue and equal participation**. Equal participation is deemed important to gather values and worldviews relevant to the R&I process, but because stakeholder participation is frequently characterized by diverse perspectives, this poses the risk of misinterpretation and conflict. Furthermore, some perspectives might dominate discussions as a result of personalities, knowledge, or institutional roles (e.g. citizens vs. scientists). Mitigating knowledge-based domination may require a thematic 'warm-up' for both citizens and scientists. Deploying a facilitator who is gender and diversity competent could also help mitigate conflict and imbalances by steering discussions and safeguarding the involvement of less vocal participants. Mutual trust among participants can be fostered by choosing an external mediator who takes on a neutral role during discussions. It can furthermore be beneficial to reduce information asymmetries by either offering or withholding information.

The RFO partners also indicated challenges related to the **accommodation of vulnerable groups**[24]. This is especially relevant as participatory processes in research funding often relate to solving real-life

[24] For critical discussions of the term "vulnerability" in the context of (participatory) research, see: Brown, K., Ecclestone, K., Emmel, N., 2017. The many faces of vulnerability. Soc. Policy Soc. 16, 497–510.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 872441.

problems. The stakeholders affected by these problems may therefore be subject to social injustice, financial issues, or other pressures and risks. Because vulnerability is difficult to define and understand, it can help to consider aspects that give rise to stakeholders' vulnerability such as their resources, abilities, experiences, identities, values, and worldviews. Stakeholders generally have a better idea of their own vulnerability. Hence, it can be beneficial to directly ask stakeholders about their perspective on this as opposed to the RFO making such assumptions itself. RFOs could also help accommodate vulnerable groups based on their own suggestions, and by compensating for the underlying aspects that give rise to disadvantages, e.g., through financial compensation, the use of translators, or the enhanced accessibility of meetings.

In the case of **stakeholder participation for the creation of funding themes/priorities**, some RFOs experienced difficulties determining how to involve both traditional stakeholders (scientists and innovators) and non-traditional stakeholders (e.g. citizens). The RFOs recognized three possible ways to involve them: (1) traditional stakeholders can propose themes, and non-traditional stakeholders can select and contextualize these; (2) non-traditional stakeholders propose themes, and traditional stakeholders select these; or (3) the proposition and selection is done collectively. While all three approaches may yield results, RFOs found that collective discussions tend to give rise to power imbalances (e.g. based on expertise and status). Allowing non-traditional stakeholders to propose themes provided many socially relevant themes, but these were not always considered scientifically relevant. Allowing traditional stakeholders to propose themes, while non-traditional stakeholders selected them streamlined the process, but runs the risk of tokenism due to limited decision-making power of non-traditional stakeholders. As such, all approaches have advantages and drawbacks, and the appropriate approach likely remains context dependent.

While skills and knowledge on ethics and participation is believed to improve stakeholder participation, **RFOs frequently lacked ethical and participatory expertise**. RFOs suggested that the ethics framework helps, but that external support from ethicists, facilitators, and recruitment agencies can further foster the quality of participation. It is nevertheless helpful to understand that organizing stakeholder participation benefits from a learning-by-doing type of approach that is flexible and open to feedback from its participants. RFOs therefore benefit from people with the right mind-set, i.e., openness, social skills, and the willingness to change things up.

Lastly, it is important to stress that **while the ethics framework strives for the highest ethical standards, this may not always be possible in practice**. Organizing stakeholder participation is an uncertain process that tends to unfold differently than planned. One RFO mentioned that "these processes seem way more resource consuming than thought in the beginning". Participatory processes are furthermore dependent on external factors (e.g. regulations, operational planning). All these challenges indicate that it is helpful to have a surplus of resources available, and to have back-up plans in case flexibility is required.

https://doi.org/10.1017/S1474746416000610 and Aldridge, J., 2015. Participatory research: Working with vulnerable groups in research and practice. Policy Press. https://doi.org/10.2307/j.ctt1t8933q

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3 Part II: Tools & Guidelines

Considering the complex relation between participation and ethics, how should participation be organized and framed? Rather than providing a list of criteria only, **this ethics framework offers a broad list of questions that should be considered**. The purpose of the PRO-Ethics Tools & Guidelines is to provide a context-sensitive roadmap in the form of questions for the design, implementation and evaluation of stakeholder participation. Because different contexts offer different opportunities and constraints, **this ethics framework provides guidelines rather than rigid rules.** The questions, considerations, and classifications below are addressing the main **ethical aspects to determine the participants and the participation modes**: who, when, how, and what for?

The consideration of these questions is meant to define how stakeholders could be identified and invited to participate in R&I processes, according to a **pluralistic ethical approach** as described in the previous section that may provide **added value** in the ways laid out above. In that vein, ethical issues are guiding these tools, comprising a list of dimensions and questions to address as **a roadmap for the diversity of methods and options of participatory approaches**. The purpose of this ethics framework is to provide tools and guidelines to decide whether participation is warranted and what actions and considerations should be undertaken in order to achieve it in an ethical manner. The most suitable participatory path in each specific case derives from a consideration of the context and the specific needs of both the institution undertaking it and of the R&I process that it is applied to. Although this ethics framework is designed primarily from the perspective of RFOs, it may likewise prove valuable for other organizations.

Below, we offer a set of questions and associated actions to consider when designing, implementing and evaluating participatory processes:

A. How should participatory processes be structured?
B. Which type of activity is targeted by the participatory process?
C. Which types of participants are targeted?
D. What are the ethical issues and risks?
E. How can equal and meaningful dialogue be fostered?
F. How should participatory processes be monitored and reflected upon?

Each of these sections includes timeline indications that are visually highlighted in the box of each specific subset. These indications serve to identify when a specific action is to be undertaken: these timelines may be cumulative in the case of an iterative action (at different stages):

- ***before*** participation (design phase of the participatory event)
- ***during*** participation (implementation of the participatory event)
- ***after*** participation (feedback following the completion of the participatory event)

Also included is a **glossary of key terms** frequently used in the context of participation in R&I processes, to help develop shared understandings and a common language to discuss these topics.

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A) How should participatory processes be structured? *[before]* *[during]* *[after]*
• ***Action A1: Understand the structural constraints you are operating under.*** *[before]* *[during]*
Reflect on the structural context you are operating in and outline existing dependencies that affect the implementation of your participatory process. Identify existing rules and procedures relevant to your process (institutional, legal, and other) and investigate how much flexibility you have to adapt them. Determine what decisions you may take freely, where you need to secure buy-in from other institutional actors, and how much decision-making power you may relay to participants. Secure a mandate and resources (time, budget, personnel) to implement the participatory process.
• ***Action A2: Identify and clarify the expected contributions.*** *[before]* *[during]*
Identify why you and potential participants are interested in a collaboration, what roles each stakeholder in a process might have, and what types of knowledge and perspectives are sought. This also needs clarity on the expected goals and impacts of the process. Transparently clarifying these from the beginning and continuously throughout the process helps to manage and align expectations on both sides, particularly regarding the impact of the process and how interactions should be structured. This also helps frame, justify, and outline participatory processes for more focused, ethical, and appropriate implementation.
• ***Action A3: Allow for flexibility when planning the participatory process.*** *[before]* *[during]* *[after]*
Stakeholder participation benefits from being organized in an iterative and agile process. Due to its complexity, unexpected nuances and concerns usually reveal themselves in-the-making. Organizational flexibility is therefore needed and can be fostered by proactive approaches to risk management. Sufficient time and resources must be allocated to the participatory process. These resources and the selected participatory methods[25] contribute to the flexibility and quality of the process and therefore require explicit consideration.
• ***Action A4: Explore possible, probable, and desirable impacts of R&I*** *[before]* *[during]*
Identify the potential social, political, institutional, economic, environmental, or other impacts that R&I processes (might) have, including potential negative impacts stakeholders would like to avoid. Try to be comprehensive and cover all potential stakeholder groups in your assessment. Impacts are best anticipated in inclusive settings and can be better understood by involving the stakeholders that are (potentially) affected. Impacts should be listed and related to the design and outcomes of participatory processes. Consider collectively what steps should be taken to mitigate risks and realize desirable outcomes.
Be mindful of the fact that all impact assessment models have a specific scope and a limited focus. They are best seen as tools to support a better structure and understanding of your participatory process and the outcomes you want to achieve. Good online resources to consult on impact assessment include:

[25] There is a diversity of participatory methods that could be employed in any given process. These should be chosen carefully, considering the intended goals of the process, the available resources, and the specificities of the stakeholder groups to be involved. For more information, see section 3.2.1 (above).

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- https://www.betterevaluation.org/
- https://www.fasttrackimpact.com/
- https://impact.nwo.nl/en/working-with-an-impact-plan
- https://www.europarl.europa.eu/RegData/etudes/STUD/2021/690031/EPRS_STU(2021)690031_EN.pdf
- https://commission.europa.eu/system/files/2021-11/swd2021_305_en.pdf

B) Which type of activity is targeted by the participatory process? *[before]* *[during]*

- ***Action B1: Define for which type of activity a participatory approach is undertaken.*** *[before]* *[during]*

An appropriate context, type and timing for the participatory process has to be selected (see below). This can be very limited, covering only one activity within a larger process, or it can comprehensive, starting already at the planning phase. Build on the impacts defined in A3 and take into account the stakeholders' relationship with, and potential contribution to, the R&I process.

Research funding organizations have a special position in R&I ecosystems. On top of funding and supporting scientific projects that build on or employ participatory methodologies, they can also involve stakeholders in RFO-specific activities, such as:

- Developing R&I strategies
- Setting funding priorities
- Defining and formulating funding calls
- Evaluating project proposals
- Mentoring R&I projects
- Monitoring R&I projects
- Evaluating R&I projects

There are a great variety of available participation formats, including citizen juries, citizen advisory boards, consensus conferences, focus groups, deliberative opinion poll, negotiated rulemaking, participatory evaluation and so on. Good online resources to consult on participatory formats include:

- https://involve.org.uk/resources
- https://participedia.net/
- Cos4Cloud Methodological Guide (Co-Design): https://zenodo.org/record/7472450#.Y9Pqii8rzs3
- Participatory AI for Humanitarian Innovation: https://media.nesta.org.uk/documents/Nesta_Participatory_AI_for_humanitarian_innovation_Final.pdf

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- ***Action B2: Remove barriers for participation.*** *[before] [during]*

Reflect on what barriers for participation might exist for different groups of stakeholders and how to address them. Barriers can include the accessibility of the location where an activity is undertaken (e.g. in terms of geographical location / distance, connectedness via public transport, and architectural design / wheelchair accessibility); the accessibility of the technologies employed for the activity (e.g. digital technologies and their related costs); the flexibility needed to participate in a process (e.g. in terms of time and money) and what your process might compete with (e.g. paid employment, care duties, health management and recuperation time, other volunteer work). Other potential barriers might arise from power structures and institutional exclusionary practices (e.g. imbalances arising within a group of participants, the participation of certain populations being vetoed by decisionmakers, or certain groups excluding themselves due to discomfort or fear of certain institutions). Develop concrete solutions to address these barriers, such as providing childcare on location, choosing accessible venues, and offering compensation for the investment. consider which participant groups you are reaching and which you are excluding.

C) Which types of participants are targeted? *[before] [during]*

- ***Action C1: Determine which stakeholders to engage and why, followed by interlinking the participatory process, context, and stakeholder types.*** *[before] [during]*

It is important to understand which stakeholders might be relevant to involve in a process, and why. This could mean including stakeholders with specific knowledge of or experience with an issue, being affected by this specific issue, or the concrete role and relative power they have within a system or process. It also entails a broader reflection on aspects such as gender, age, socio-economic background, dis/ability, geographic location, as well as stakeholders' overall proximity to the R&I process. These specifications allow for a better understanding of the field and the identification of groups that may have been overlooked. It also helps to understand the potential needs of participants to meaningfully take part in a process. Mapping potential stakeholders and their interests ensures that the type of participatory process appropriately addresses both the context and the stakeholders involved[26]. Consider additionally what type of representation is needed to obtain the desired contribution. For instance, do participants need to reflect the diversity of society, or should the process focus on specific stakeholders? Matters of representation become important when interested in, for example, specific user groups or marginalized stakeholders.

- ***Action C2: Determine how participants should be recruited, taking into account stakeholder representation, selection bias, and feasibility*** *[before] [during]*

After potential participants are identified, it is crucial to consider how they should be recruited, taking into account stakeholder representation, selection bias, and feasibility. The planning and execution of recruitment efforts often takes more time and investment than expected and may be a prolonged, iterative process in longer-lasting participatory endeavors. Reflect on the benefits and drawbacks of recruitment techniques (e.g. feasibility versus selection biases), and target your approach to

[26] Working with non-scientific participants in a scientific context entails a meeting of different frames of reference. In turn, it is important to understand the roles of R&I actors (such as researchers) and participants, including the scopes and limits of their responsibilities. In particular, it is important to address questions of research integrity and safeguard the quality of the scientific process while taking care not to exploit any involved actors.

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stakeholders based on their specificities and needs as identified in C1. While recruitment can be challenging, stakeholders are more inclined to participate if the process is in their direct interest. Timing can be a decisive factor. Consider, for instance, whether holidays or other periods obstruct participants' involvement. Some possible recruitment techniques are:

- **Existing organizational networks:** The existing stakeholder network of the organizer provides the opportunity to recruit participants. Stakeholders can for example be contacted through social media or newsletters.
- **Snowballing techniques:** Asking participants for referrals to other potential participants can enlarge the existing pool of participants.
- **External recruiters:** Recruitment can be outsourced to parties with extensive experience. Make sure that recruiters are sensitive to ethical issues related to stakeholder participation.
- **Multiplier partners:** External partners (e.g., municipalities, intermediaries, and influencers) can help recruitment efforts by providing access to their stakeholder network. Persuading these multipliers to collaborate tends to be easier when they share similar interests with the participatory process.

D) What are ethical issues and risks? *[before] [during]*

- ***Action D: Identify ethical issues and tackle them appropriately.*** *[before] [during]*

With clarity on the participatory process and potential participants it becomes easier to assess potential ethical issues and determine where and how a process should be adapted. Ethics experts could help identify, understand, and mitigate ethical issues.

Consider the following potential issues in relation to your R&I processes:

- **In project proposals:** Issues of human dignity, power, intellectual property, privacy, and data protection, transparency, and biases (e.g., gender bias, bias towards the able-bodied, etc.) should be considered when planning the process and outcomes of research and innovation.
- **In project executions**: Issues relating to personal data; discrimination; stigmatization; fixation on technology acceptance; vulnerable groups; privacy; safety; social responsibility of researchers; informed consent; social roles in the application context; use of ethically sensitive findings; manipulation and guardianship through technology.
- **In evaluation processes:** Common ethical risks in relation to stakeholders' legitimacy, lack of ethical expertise; communication of funding calls; conflicting interests.

Consider the following issues that may return in general:

- ***Informed consent:***
  - Informed consent procedures should be employed to build a baseline understanding of the process among its actors.
  - Ensure you choose an appropriate informed consent process and format for the target group.
  - Use accessible language, remain within a reasonable length, and consider creative methods such as movies and comic strips, or dynamic informed consent to address groups farther away from the R&I system.
- ***Financial compensation:***
  - Determine if, to whom, and how much financial compensation should be given.
  - Compensation should address barriers to participation. Avoid that financial compensation becomes an incentive in itself.
- ***Methods:***
  - Consider that when participation is made a mandatory requirement for funded projects, this might raise the hurdle for diverse and new institutions to access funding. Support and training could mitigate this risk.

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- Identify the adequacy of the selected participatory process regarding i) if participation is warranted in the given project; ii) if the stakeholder participation would benefit from additional support.

- ***Knowledge / awareness:***
  - Consider what means are needed to help participants understand R&I. For example, participants can be given a thematic 'warm-up' and should be given enough time to process information.
  - Identify what knowledge is needed (scientific/technical background) for the participatory process; foresee what type of group dynamics may emerge as a result of information asymmetries; and ensure that potential ethical problems that have been spotted find the required expertise.
- ***Disadvantaged stakeholders***
  - Identify if, who, and how stakeholders may be disadvantaged. This can partly be determined on the basis of participant input.
  - Engage with disadvantaged stakeholders prior to the participatory process to understand their needs.
  - Customize participatory processes to disadvantaged stakeholders so that they can participate in a meaningful way.
- ***Research integrity:***
  - Identify if (and how) the participatory process might affect the researchers' integrity.
  - Align the participatory process with frameworks, standards, and/or codes of conducts on research integrity.[27]
- ***Assess the overall risk to actors in the process,*** *including*
  - physical (direct harm, long-term harm)
  - psychological (traumatizing methods, sensitivity of questions, …)
  - social (stigmatization, discrimination, …)
  - data protection, privacy, confidentiality
  - insurance status of participants

E) How can equal and meaningful dialogue be fostered? *[before]* *[during]*

- ***Action E: Consider how equal and meaningful dialogue can be established and safeguarded in light of participants' characteristics and vulnerabilities.*** *[before]* *[during]*

Ensure that the design and implementation of participatory processes foster equal and meaningful dialogues between participants. Contemplate whether including an experienced (external) moderator could improve the process. Try to foresee what forms of representation, participant types, and reciprocal relationships are applicable, taking into account expected power imbalances and the desirability hereof. The following non-exhaustive list of considerations are important:

- **Representation:** Consider who is excluded and included by reflecting on the balance between diversity and representation (proportionality); composing a set of participants while taking into account the possible (over-)representation of minorities.
- **Power:** Make sure all participants are heard and try to reduce power imbalances. These imbalances may result from the participants' differences in personality, capacity, knowledge, and resources. It can, for instance, help to reduce information asymmetries by providing or withholding information. In addition, try to identify (potential) conflicts that need to be navigated. A skilled neutral facilitator or ombudsman can play an important role.
- **Empowerment:** Take measures to enable your participants to actively participate in, influence, and benefit from the R&I process and its outcomes. Allow them to develop ownership of the process by giving them true decision-making power.

[27] Most prominently, this includes the ALLEA European Code of Conduct for Research Integrity. The most current version of this living document can be accessed via ALLEA's website: https://allea.org/code-of-conduct/

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- **Exploitation:** When including minorities and/or vulnerable stakeholders, ensure that they are not disproportionately burdened with the participatory process. If needed, provide forms of adequate (case-by-case) compensation either before, during, or after the process.
- **Vulnerability:** Recognize that there are many aspects to vulnerability that are often difficult to identify. Pay specific attention to aspects that give rise to vulnerabilities such as one's experiences, abilities (including language skills), identity, resources, values and worldviews. Participants themselves are best positioned to recognize whether they are vulnerable. Trust their judgement and accommodate adequately for their vulnerability.

F) How should participatory processes be monitored and reflected upon? ***[before]*** ***[during]*** ***[after]***

- ***Action F1: Monitor and collectively reflect on the participatory process and outcomes.*** ***[before]*** ***[during]*** ***[after]***

To safeguard ethical aspects of participation, it is important to monitor (possible) issues during the implementation and evaluation of a process, as laid out in action-set D. This can be done using qualitative and quantitative performance indicators and through continuous feedback from participants. Continuously and collectively reflecting on (un-)expected performances and outcomes helps improve current and future participatory processes. Expectations may be adapted if needed, following a possible deviation from pre-set monitoring indicators.

This action is complementary to A2 and A3.

- ***Action F2: Reflect on the following aspects.*** ***[during]*** ***[after]***

- Verify if and how matters of representation and inclusion are/were addressed throughout the participatory process.
- Consider (the weight of) input from participants in the final decisions of participatory processes.
- Determine whether the goal of the participatory process will be or has been achieved.
- Identify how the biases of your participatory activities affected the process and its results.

- ***Action F3: Launch a transparent process allowing participants to interact and reflect*** ***[during]*** ***[after]***

Depending on the scope of the participatory activity and the organizational capabilities, a collective reflection on the participatory process helps to learn about the participants' experiences. This may be done through a short focus group or survey. Such feedback should be used as the main assessment of the process, indicating potential needs for improvement.

- ***Action F4: Communicate how the input of participants is used.*** ***[before]*** ***[during]*** ***[after]***

Reflect on the input of participants, its added value, and how it did (not) feed into outcomes. Why and how were certain decisions made? Communicate this to participants, and ensure they feel valued. In some cases, this may include a financial compensation (see also action D) or an official acknowledgement.

- ***Action F5: In view of future reference, all reflections answering the framework's actions could be documented and saved.*** ***[after]***

Future participatory processes can learn from the current stakeholder participation when documenting and archiving answers to the above-mentioned actions. It furthermore supports matters of accountability.

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G) Glossary

The categories and definitions outlined below reflect the work undertaken in PRO-Ethics and emerged as common references during the implementation of the project. They cover important concepts for the implementation of ethical participatory processes, particularly in the context of the activities of research funding organizations.

Bias

In the context of our work, bias is mainly relevant in two ways: First, as often unconscious preconceived opinions, beliefs, or attitudes that influence how stakeholders in R&I define and address problems, set up processes, and perceive and interpret data. This might entail a preference for the inclusion of particular stakeholder groups over others (or a perceived greater validity of some perspectives), a predilection for specific outcomes, and an overall skewing of the process towards certain – often hegemonic – power structures. Second, as systematic errors in the vein of statistical bias that distort the process as well as the collected data and its analysis. While often unintentional, flawed methodologies, selection biases and information biases can have significant ramifications for the quality of an R&I process and its outcomes, while also negatively impacting its participants. Thus, it is essential to be mindful of potential biases and take active steps to identify and address them in order to ensure the quality and equality of an R&I process.

Citizens

While "citizen" is not a term that might be employed uncritically[28], we decided to draw on this category as an established umbrella term that includes the general public, lay people, and citizens as persons (or collectives) with civic expectations[29]. Moreover, since end-users can be categorized as citizens as well, this distinction serves to underline the general dimension of involvement, referring to the broader sense of "public participation".

Civil society organizations

Civil society organizations are not-for-profit organizations that may represent specific citizen groups, but have different knowledge and leverage than individual citizens. They may defend interests, often professional interests (trade unions), or causes (e.g. animals, environmental issues), or rights (e.g. minorities, women).

Communication and Dissemination

Employing the term in the context of R&I processes, communication refers to the sharing of contents and results of R&I endeavors in an accessible manner, increasing its public visibility. It is distinguished from dissemination by its primary target groups, as dissemination is targeted more towards a scientific audience, but also policymakers and industry representatives. Both communication and dissemination tend to be one-way exchanges of information towards any type of stakeholder.

[28] See e.g. Eitzel, M., Cappadonna, J., Santos-Lang, C., Duerr, R.E., Virapongse, A. West, S.E., … Jiang, Q., 2017. Citizen Science Terminology Matters: Exploring Key Terms. Citizen Science: Theory and Practice. pp. 1-20. https://doi.org/10.5334/cstp.96

[29] In this category, the main boundaries for the "citizens" category are anchored in the citizens/stakeholders distinction.

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Co-Creation

We use co-creation to cover the comprehensive collaboration between all stakeholders of an R&I process from its inception to its conclusion. Hailing more from the context of R&I project, co-creation covers all steps of the research cycle, from the definition of a research question to the evaluation of a project and the assessment of its impacts. While this has not yet been similarly established as a valid approach, this process can be mirrored in the context of the R&I funding cycle, starting from the development of the R&I funding strategy and ending with the evaluation and impact assessment of funded projects and the funding program overall. As an umbrella term, co-creation also covers the concepts of co-design (collaboratively defining a problem and its solutions by designing technologies, processes and solutions), co-production, and co-development.

Collaboration

While collaboration broadly covers the process of people or organizations working together to achieve a goal, in the context of our framework it is important that collaboration is equal and meaningful, i.e. allow all involved stakeholders to contribute and impact the process and its outcomes.

Consultation

Processes of engagement (see definition of 'engagement') where any group of citizens or stakeholders are asked to provide input on an issue, process, policies or programs. These inputs are not guaranteed to be taken up in a meaningful manner, in that they make an impact on processes and their outcomes.

Diversity, Equality/Equity, Inclusion

Diversity as a term reflects the many different ways we understand and categorize people (e.g. according to gender and gender identity, sexual orientation, race and ethnicity, dis/ability, socioeconomic status, etc.). Inclusion is about providing equal access to take part in a process or activities. Thus, diversity in participation is about including a range of perspectives and experiences to create outcomes that work for more than just a few. In this context, equality refers to everyone being treated equally and receiving the same opportunities and resources, while equity is about addressing individuals' specific needs. It is essential to address bias and discrimination to achieve both equality and equity for diverse groups of people, but also to ascertain the quality of R&I and mitigate potential harms it may create[30].

Empowerment

Empowerment is about enabling individuals and groups to actively participate in, influence, and benefit from R&I processes and their outcomes. It aims to distribute power equitably and in turn have a positive impact both on the concrete processes at hand and wider society. Empowerment can entail the provision of knowledge, ensuring that people have access to and an understanding of scientific findings. And it can entail participation, which is about inviting a broad range of relevant stakeholders to the table – including also underrepresented and marginalized groups – while ensuring that all participants in a process are heard and have a hand in shaping the course of the R&I endeavor.

[30] Ruzycki, S.M., Ahmed, S.B., 2022. Equity, diversity and inclusion are foundational research skills. Nature Human Behaviour 6, 910–912. https://doi.org/10.1038/s41562-022-01406-7

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End-users

End-users are the (presumed) groups and individuals intended to make use of the end product (including solutions and services) of an R&I process. While the concrete (groups of) end-users cannot always be foreseen in their entirety, assumptions about their needs are always inscribed into a technology, process, service or solution. Engaging potential end-users in the development of R&I is intended to better meet their needs, and thus heighten the chance of the outputs to be useful and used.

Engagement

In this document, engagement is used as an umbrella term for different forms of one-way and two-way exchange as well as collaboration between stakeholders from R&I (such as professional researchers and research funding organizations) and stakeholders beyond the R&I system (such as citizens, end-users, civil society organizations, NGOs and so on). This may include forms of communication, consultation, or more intense approaches to participatory engagement such as co-design and co-creation.

Ethics

Ethics is the discussion of and reflection on moral values and norms (in short: morality). The adjective "moral" indicates that those values and norms have a special status, typically taking the form of obligations and prohibitions. Their special status is manifested by the fact that moral rules are accompanied by praise and blame, rewards and punishments, to motivate people to live according to these norms and values[31]. The adjectives ethical and moral are often used interchangeably.

Evaluation (of projects and programs)

This category encompasses several types of evaluation: evaluation of project proposals (i.e. the ethical and scientific evaluation) as part of the selection process intervening in funding schemes; the interim and ex-post evaluation for projects and programs that received funding; and program evaluation. Evaluation reflects on the implementation and results of an R&I endeavor to ascertain its overall quality, and can focus both on processes and outcomes/results. In contrast, impact assessment always focuses on the broader long-term effects of an R&I process.[32]

Experts

This category serves to identify individuals who are enrolled as (internal or external) experts in R&I processes. In the context of this document, we include both lay and professional experts in this category. Thus, citizens may for instance be involved in an R&I process as 'experts by experience', providing insights into their lifeworlds and value systems. Experts can also be individuals with any sectoral/disciplinary expertise (e.g. with a background in medicine, psychology, sociology, philosophy — among others). Consequently, participants might bring different kinds of expertise and different types of knowledge (e.g. tacit, formal, endogenous, living world, etc.) into an R&I process.

[31] Swierstra, T., 2017. Introduction to the Ethics of New and Emerging Science and Technology. In: R. Nakatsu et al. (eds.), Handbook of Digital Games and Entertainment Technologies, Springer, Dordrecht. https://www.doi.org/10.1007/978-981-4560-50-4_33

[32] For a closer look at the complexities of evaluating participatory processes – specifically in the context of citizen science – see Schaefer T., Kieslinger B., Brandt M., van den Bogaert V., 2021. Evaluation in Citizen Science: The Art of Tracing a Moving Target. In: Vohland K. et al. (eds) The Science of Citizen Science. Springer, Cham. https://doi.org/10.1007/978-3-030-58278-4_25

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Fairness

As a concept related to diversity, equality/equity, and inclusion, fairness encompasses ensuring equal access to resources and opportunities, unbiased decision-making processes, and outcomes that don't unjustly advantage or disadvantage certain groups. Like other ethical principles covered here, the specific interpretation and implementation of fairness may vary depending on the context.

Impact Assessment

Impact assessment focuses on the long-term and broader effects of an R&I process. It entails the definition of concrete effects to be achieved, (qualitative and quantitative) indicators for achieving this impact, and instruments to measure these indicators. Evidence is then gathered and analyzed to show concrete results. Depending on the concrete focus of an R&I process, it might aim to achieve societal, political, institutional, scientific, economic, environmental or technological impact. As impact necessarily unfolds over time, change usually unfolds beyond the lifetime of an R&I process, making it difficult to substantiate.

Monitoring

The systematic observation of implementation of funded projects and their results in the context of RFO funding schemes. Monitoring is usually carried out internally with support by external experts, e.g. for interim or final reviews. Ex-post monitoring of results can also involve other stakeholders, in addition to the involvement (feedback) of program beneficiaries.

Participants

Participants are defined as persons who take part in participative processes. In this document, we primarily use this term for non-traditional stakeholders of an R&I process such as citizens in the broadest sense, (end)-users of a technology, residents of an areas, people affected by an issues, entrepreneurs, project beneficiaries, and so on. Participants are engaged in such processes due to their specific knowledge, perspectives and/or interests they bring to the table. Participants can be individuals or representatives of institutions or groups and may include vulnerable groups such as patients, children, or older adults. Often, there is an overlap in categories of participants, as individuals may draw expertise from different fields and experiences. In each case, it is important to develop an awareness of the specificities of the participating persons and address them in the design and implementation of a participatory process.

Participation

While there is no uniform definition of participation, participation is frequently described as a form of engagement that allows (potentially) affected stakeholders to partake in decision-making for R&I. There is a graduation to the intensity of participatory processes, ranging from limited and short-lasting involvement in an R&I endeavor to a comprehensive collaboration between all stakeholders of an R&I process from its inception to its completion. Truly participatory practices empower stakeholders to shape decisions in accordance with their own values and worldviews.

Privacy

Privacy is a fundamental right that refers to a person's ability to control their personal information and decide when, how, and to what extent such information is shared with others. There are clear regulations and compliance procedures structured by the GDPR and other relevant national and international law, which entail provisions for the collection, processing, dissemination and storage of personal data and

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the gathering of (informed) consent. In participatory R&I processes, informed consent is especially important as it opens the conversation on the focus and context of a process, its goals, any associated risks, the intended scope of participation and roles of involved stakeholders, as well as the expectations people bring to the table. It is thus an essential tool for creating transparency from the very beginning.

Program design

In the context of research and innovation, program design refers to the identification of program objectives and of R&I priorities, resulting in the definition of funding opportunities while adhering to specific regulations.

Research ethics and research integrity

Research integrity refers to the quest of making research findings and the process in which they are produced (i.e. data, methods, interpretation and presentation/reporting) meet established and appropriate scientific, legal and professional standards. By comparison, research ethics pertains to the moral issues that occur in the research design and its implementation, for instance in relation to the protection of humans, animals, the environment, data as well as the proper protection of other objects.[33]

Representation

The substitution of an individual or class in place of a person (such as a sibling of a severely ill person who is not able to express her/his own preferences). Representation needs to be fair, but the precise meaning of fairness is context dependent. This may mean that some contexts require additional efforts to include particular stakeholders.

RFO activities

In the context of PRO-Ethics, RFO activities and processes refer to the entirety of the R&I funding cycle: 1) strategy development; 2) program/funding scheme development; 3) call topic development and call launch; 4) proposal evaluation; 5) project implementation and monitoring (which might include training and support of project beneficiaries); and 6) project/program evaluation and impact assessment.

Scientists and other research institute representatives

Scientists (any scientific or technical field) or other representatives of research institutions involved in RFO processes either for their individual expertise or for their affiliation to a research institution, but speaking primarily for themselves (as opposed to stakeholders involved explicitly as representatives of their organizations). This category also includes researchers meant as physical persons working for a legal entity (SMEs, Universities, Research Institutes) conducting research and to whom has been granted public or private funding to do so.

Stakeholders

In the context of R&I funding and program development, the term “stakeholder” usually refers to businesses, institutional representatives and other strong interest groups that are traditionally included in the processes of R&I funding. For PRO-Ethics, we broadened this definition of stakeholders to anyone with a stake in an R&I process, i.e., anyone who may affect or be affected by it in any way. In the project we focused mainly on the participation of “non-traditional” stakeholders, by which we mean anyone not

[33] Braun R., Ravn T. et al. (2019) RE/RI expert set of indicators for e-database. ENRI Deliverable 6.2. ENRI Network.

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usually included in the activities of research funding organizations and other R&I processes. These might include, among others, citizens in the broadest sense, residents of an area, end-users of a technology, people affected by an issue, beneficiaries of funding calls, entrepreneurs, and others. Due to the broad nature of our understanding of stakeholder, our use of the term throughout the document entails both traditional and non-traditional stakeholders as well as anyone else involved in an R&I (funding) process such as research and program managers, scientists, experts/consultants, (external) facilitators and so on.[34]

[34] This is in line with the ISO 21500 definition of the term. See https://www.iso.org/standard/75704.html

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