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RESEARCH ARTICLE

Too many hats: The challenges of opening up funding agencies to ethical stakeholder participation

[version 1; peer review: 3 approved with reservations]

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v1 **First published:** 10 Feb 2025, **5**:47
https://doi.org/10.12688/openreseurope.18761.1
Latest published: 10 Feb 2025, **5**:47
https://doi.org/10.12688/openreseurope.18761.1

Abstract

Background

As the processes of scientific knowledge production and innovation are increasingly opened up to broader audiences, research and innovation funding agencies (RFOs) have emerged as a new site of public engagement. While public engagement in R&I has a long tradition, RFOs have little experience with such practices, leading to potential ethical pitfalls and a need for new ethics governance approaches.

Methods

Eleven participatory pilot projects were implemented by RFOs in two phases. Pilot data were collected via structured reporting templates, narrative pilot stories and final pilot reports. In addition, more open exchange took place in peer-learning workshops and meetings, which were protocoled and partly transcribed. These data were analyzed in a qualitative content analysis following Mayring (2014).

Results

This paper provides insights into drivers and barriers to ethical participation in the activities of research funding agencies and offers recommendations for enhancing the inclusivity and integrity of RFO practices. It describes the specificities of (ethical) engagement in RFO activities as elicited from our data along three axes: 1) structures, in terms of how funding agencies must proactively lay the groundwork for enabling ethical participatory processes; 2) processes, especially in terms of managing the different steps involved in recruiting and

Open Peer Review

Approval Status ? ? ?

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version 1 10 Feb 2025	? view	? view	? view

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engaging participants; and 3) actors, in terms of the roles and responsibilities the involved stakeholders may inhabit.

Conclusions

The paper identifies various drivers of ethical engagement, including gaining an understanding of the structural context conditions within which participatory activities are implemented, identifying and addressing barriers to participation, and managing the expectations of all stakeholders involved in the process. Looking into potential instruments for ethical governance for funding agencies, the merits of ethics self-assessment, ethics review and external support are discussed. Concrete recommendations are formulated for teams and organizations planning to implement participatory activities in the future.

Plain language summary

This paper explores how ethical collaboration can be ensured when public actors are invited to contribute to the work of research funding agencies. Usually, funding agencies work with academics and other experts to decide how to distribute funding for research and innovation. When engaging lay people for such tasks, care must be taken to treat them respectfully and to enable them to contribute to the tasks in a meaningful way, so that their time and efforts are valued. It is also important to ensure everyone feels comfortable sharing their opinions and hierarchies do not have too much of a negative effect on the collaboration. The paper discusses potential difficulties in achieving this meaningful collaboration and suggests possible solutions to these problems. It also proposes ways to govern ethical conduct, that is, to make sure someone is clearly made responsible for looking out for ethical problems and for actively trying to address them. At the end, the paper also gives clear recommendations for planning and implementing participatory activities in research and innovation.

Keywords

Stakeholder engagement, public participation, research ethics, research funding organizations, ethics governance



This article is included in the Horizon 2020 gateway.



This article is included in the Research Ethics and Integrity collection.

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Author roles: Schuerz S: Conceptualization, Data Curation, Formal Analysis, Investigation, Methodology, Project Administration, Writing – Original Draft Preparation, Writing – Review & Editing; **Fetting C**: Formal Analysis, Investigation, Writing – Review & Editing

Competing interests: No competing interests were disclosed.

Grant information: This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No [872441] (PRO-Ethics).
The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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How to cite this article: Schuerz S and Fetting C. **Too many hats: The challenges of opening up funding agencies to ethical stakeholder participation [version 1; peer review: 3 approved with reservations]** Open Research Europe 2025, **5**:47 https://doi.org/10.12688/openreseurope.18761.1

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Introduction

"Engagement, then, is any two-way interaction between research and its publics: beyond this there are "myriad ways" in which it can be carried out" (Davies, 2013: 67)

Over the last decades, the engagement of broader stakeholder groups in research and innovation (R&I) has become a widespread phenomenon, integral to approaches such as citizen science (CS), open science (OS), transdisciplinary research (TDR), and the quadruple/quintuple helix models of innovation (Carayannis *et al.*, 2012; OECD, 2020; OECD, 2022; UNESCO, 2021; Vohland *et al.*, 2021). Similarly, open collaboration with knowledge actors beyond the academic system has been an ever-growing policy priority both in European national and European Commission (EC) funding schemes, outlined in a commitment to Responsible Research and Innovation (RRI) and OS practices in both the EC's current and former framework programs (EC DG RTD, 2021a; EC DG RTD, 2021b; Marschalek, 2018; Rip, 2014; Zwart *et al.*, 2014).

The present paper focuses on participation in the context of publicly funded research funding organizations (RFOs), which are institutions central to the development of national and regional research agendas and funding schemes. As such, they operate at the intersection of science and policy. For this reason, we follow a broad definition of public participation suggested by Rowe and Frewer for the policy context, as *"the practice of consulting and involving members of the public in the agenda-setting, decision-making, and policy-forming activities of organizations or institutions responsible for policy development."* (Rowe & Frewer, 2004: 512) Throughout this paper, this term is mostly used synonymously with stakeholder engagement, with 'engagement' signifying any two-way interaction between publics and decision-makers (Davies, 2013), and 'stakeholders' signifying our main group of interest, although we broaden this term to mean any individual, group or organization with a stake in an issue (Frooman, 2010). This means anyone affected by or with the power to affect the issue at hand, which, depending on the specific context, may entail e.g. citizens (in terms of inhabitants of a region), special interest groups, civil society organizations, or end-users of a technology. Participants, then, are any stakeholders actively engaged by a funding agency in their activities. This paper will outline in greater detail what participation in the activities of funding agencies may look like across different phases of the R&I funding cycle, and at different intensities and timescales. Finally, public engagement is used interchangeably with public participation throughout this paper, following Delgado *et al.* (2011).

There are a variety of rationales for pursuing participatory engagement in R&I. Following the language outlined by Stirling (2008), the *instrumental imperative* sees the overall effectiveness of scientific and political interventions as an important factor for funding and supporting research endeavors. Participatory engagement becomes an essential component of maximizing impact in a utilitarian sense – achieving specific and predetermined goals – and thus follows a rather narrow perspective of stakeholder needs to be addressed (e.g. developing a technology solution to support informal caregivers). By involving a wider group of individuals and organizations affected by an issue, solutions can be developed with stakeholder input or even from the bottom-up, in dialogue with diverse epistemic cultures[1], allowing for more targeted ways of addressing concrete problems and a subsequently increased chance of uptake of outcomes. (Chang & Taylor, 2016; Trischler *et al.*, 2018) The same is true for the *substantive imperative*, which broadens the scope of the instrumental rationale beyond specific interests to allow for broader, socially negotiated outcomes to be sought (Stirling, 2008). Here, participation is seen as a way of addressing complex societal challenges and a promising means of eliciting sustainable societal transformation (e.g. achieve the EU Mission to Restore our Ocean and Waters). Participation is sought e.g. to enhance scientific knowledge through varied perspectives and scale data collection which in turn increases the societal relevance of research and allows for a better evidence-base for political decision-making, in turn raising its legitimacy. (Fung, 2009; Schneider *et al.*, 2019; Turrini *et al.*, 2018; Wiarda *et al.*, 2023b) It also builds capacity within and empowers communities to anchor societal change and create opportunities for individuals to learn and adapt habits to elicit sustained behavioral change, or to align research efforts with broader targets such es the Sustainable Development Goals (SDGs). (Bonney *et al.*, 2016; Schaefer *et al.*, 2021; Nonet *et al.*, 2022; Pateman & West, 2023) Finally, the *normative imperative* approaches participation as a fundamental human right, which promotes inclusion and facilitates broader civic participation in policy-relevant debates and decision-making processes. By appreciating the diversity of knowledge producers, it creates normative pressure for fair and reasonable collective decisions and thus allows for an equal sharing of the benefits of science among civil society – regardless of the concrete ends to be achieved. This, in turn, may also lead to a more informed public and strengthen trust in science and governance. (Bogner, 2012; Stilgoe *et al.*, 2013; Stirling, 2008; Turrini *et al.*, 2018; UNESCO, 2021).

At the same time, such rationales have been extensively questioned from several sides, bringing into focus a variety of potential pitfalls and challenges with significant ethical implications. Returning to the rationales outlined above, the instrumental imperative may lead to an over-reliance on problem-driven

[1] Following Karin Knorr-Cetina (2007), the concept of epistemic cultures puts into question the idea of (scientific) knowledge creation as a purely technical and rational procedure. Rather, we need to understand knowledge production as inherently social and symbolic, culturally embedded in "sets of practices, arrangements, and mechanisms bound together by necessity, affinity, and historical coincidence" (Knorr-Cetina, 2007: 67), which together make up the machinery of the knowledge construction process. Epistemic cultures shape how science is done within different fields and were subsequently put forth to explain the difficulties arising in inter- and transdisciplinary research (see e.g. Mørk *et al.*, 2008). Applying this lens to science-society-collaborations, we may also interpret such endeavors as a collaboration between different epistemic cultures, both internal and external to the science system. Irwin and Michael (2003) suggested the term "ethno-epistemic assemblages" to denote the combinations of lay and professional experts, as well as non-human actors such as technologies and concepts, from which new discourses, practices, and theories emerge.

strategic research with predefined ends and no real openness to participant input (Stirling, 2008; Voß, 2015). Simultaneously, an overreliance on impact logic runs the risk of inserting a neoliberal logic of economization into the science system and aligning public policy with market priorities (Hallonsten, 2021; Hydén, 2016; Nowotny *et al.*, 2003), while there is still a lack of systematic evaluation demonstrating the effectiveness of participatory engagement (Marschalek, 2018; Petts, 2008; Turrini *et al.*, 2018). Within both the substantive and normative imperatives, enabling meaningful participation has been put forth as a challenge, due to structural and societal barriers, including a lack of commitment from decision-makers (Bauer *et al.*, 2021; Bogner, 2012; Irwin, 2014; Pateman & West, 2023), the difficulties of actually taking up and integrating participant input (Felt & Fochler, 2008; Schuurbiers & Fisher, 2009; Stilgoe *et al.*, 2014), as well as the resources needed for implementing truly participatory research and innovation, which often make them untenable both for participants and for the scientific process in which they would be involved (Delgado *et al.*, 2011; Fung, 2009; Turrini *et al.*, 2018). Similarly, fears over the potential exploitation of participants have been raised (Burgess & Chilvers, 2006; Tõnurist & Surva, 2017), as have concerns regarding the integrity and rigor of research conducted with knowledge actors from beyond the science system (Balázs *et al.*, 2021; Schuurbiers & Fisher, 2009) that might not be "knowledgeable publics" (Jasanoff, 2005: 235), and the connected challenges of finding recognition of citizen science contributions in mainstream and elite science (Turrini *et al.*, 2018), as well as the risk of participatory processes being co-opted by dominant interests – be they those of scientists, policymakers, interest groups, or just the loudest voices in the room (Kleinman *et al.*, 2011; Parker & Mintzes, 2023; Powell & Colin, 2008). Biases in participation and lack of diversity may skew research focus and outcomes (Marschalek, 2018; Pateman & West, 2023), while the participatory activity might be treated as a box-ticking exercise (Wilsdon & Willis, 2004), the impacts of such processes might be limited, and unrealistic expectations may be raised – which, when unable to be met, may lead to disappointment and disenchantment with participation or the science system overall (Bogner, 2012; Soneryd, 2015).

With regard to stakeholder engagement in research itself, these ethical implications and challenges have already been discussed extensively. When it comes to stakeholder engagement in research funding, however, the conversation is only just beginning. While some R&I funding agencies have long experience with some form of participation in their processes – especially in the context of Public and Patient Involvement and Engagement (PPIE) – there is as of yet not the same level of standardization to be found as in R&I projects. (den Oudendammer *et al.*, 2019; Rowe *et al.*, 2010; van Bekkum & Hilton, 2014) As such, there is no established best practice on how to organize, implement and evaluate participatory processes in this context to ensure their quality – and to understand and meet ethical requirements inherent to such endeavors.

In this paper, we start with a theoretical exploration of participation in R&I from the perspective of research ethics. We then outline the core business and particularities of funding agencies as elaborated in the European funded PRO-Ethics project. Diving into the practicalities of participatory engagement in R&I, we discuss in-depth the specificities and challenges of ethically engaging wider stakeholder groups in the activities of research funding organizations (RFOs) as we encountered them in PRO-Ethics, sharing the results of our inquiry into existing gaps in theory and practice, as well as identified drivers and barriers of ethical participation. Finally, we elaborate recommendations to assist funding agencies and policy makers in creating, adapting and evolving their ethical frameworks for participatory research in an attempt to bridge theory and practice.

Research ethics and participation

In the broadest sociological sense, ethics is about how people should behave towards others (Sayer, 2011). Transferred to the context of R&I, it can be – and has been – argued that researchers have a special obligation to the public for the privilege of conducting research (Kalichman, 2006). But what does this obligation mean in practice? There are different approaches to this question, ranging from deontological ethics (e.g. acts are inherently right or wrong, such as plagiarism) to teleological ethics, where the outcome matters (e.g. from stem-cell research we can develop new medical treatments). It can also relate to virtues ethics, discussing the characteristics researchers should exhibit (e.g. honesty, prudence, compassion, thoughtfulness). Many of these ethics are already implicit in the codes of scientific conduct which serve to formalize and institutionalize ethics to various degrees. While all these approaches have their usefulness in understanding and assessing research ethical questions, they quickly show their limitations when confronted with the complexities of participatory processes in R&I, where vastly differing understandings, needs, cultures, capacities, and expectations collide. (Rachels & Rachels, 2012; Williams & Moore, 2006). Here, approaches such as "ethics of care" can become helpful, which situate ethics on the smallest scale of direct personal relationships, where caring takes place in an interconnected web of mutual obligations and commitment. Ethics move from the universal to the specific, putting into focus the concrete people involved and taking into account their particularities. Such an approach also accounts for the fluidity and uncertainties of interpersonal processes that cannot be disentangled from their social, societal and historical embeddedness. (Miller & Bolton, 2007; Rachels & Rachels, 2012; Williams & Moore, 2006). Applied in a critical manner, one vital contribution of such an approach is its openness to different epistemic cultures in the form of (sub-)cultural differences. Reflections on cultural biases, the specificities of epistemic positioning and their impact on participatory knowledge production – as well as the practical application of ethical principles within specific cultural contexts – are essential to decide on appropriate solutions to ethical conundrums in participatory R&I. (Hudson, 2009; Miller & Bolton, 2007)

Another important frame of reference is the governance and concrete application of these often very abstract ethical values and principles. While ethical standards for conducting science are in no way a new phenomenon, currently established approaches

to the governance of research ethics have been strongly shaped by the atrocities committed within the National Socialist regime under the guise of medical research (Weindling, 2004), which framed participation as a biomedical issue from the outset. Since then, ethics governance has mostly been implemented through ethics review procedures, which are an important, but imperfect regulatory instrument to safeguard ethical conduct in participatory R&I projects. Such reviews are usually set up as one-time appraisals rather than processes. They can be situated both at the proposal stage of a project – such as the European Commission's (EC) ethics self-assessment integral to each proposal – but also after a grant has been awarded. Approval via research ethics committees (RECs) or institutional review boards (IRBs) might be required by laws (e.g. on clinical trials), via institutional standard procedures, but also e.g. by RFOs via funding guidelines. (Ashcroft, 2003; Miller & Bolton, 2007) In any case, these procedures have become increasingly formalized throughout the European R&I system. While national legislations, domain-specific best practices, and the requirements of funding bodies still differ significantly across the European Research Area (ERA), most European academic institutions – from RECs to research performing organizations (RPOs) – tend to follow similar conceptualizations of research ethics. These include on the most basic level the preservation of human dignity and autonomy, the non-maleficence and beneficence of research (including an assessment of risks and benefits), and the safeguarding of justice as an umbrella term for principles such as fairness, equality, and the equitable distribution of resources (expressed for instance in a fair selection of participants) (see e.g. EC DG RTD, 2021b).

However, ethics reviews often fall short in addressing the ethics of participation. Current research ethical values, principles and practices – especially those focused on the involvement of human subjects – cannot be disentangled from their historical roots in biomedical research contexts and might not be equipped to accurately assess the broader implications brought about by complex research endeavors involving stakeholders as active participants in, rather than subject of, research (Bernstein *et al.*, 2021). As a result, moral and regulatory considerations might come into conflict, as frameworks of mere compliance are insufficient to address the complexity of participatory engagement in R&I, which call for enhanced reflexivity and responsibility throughout the engagement process – and not just at the beginning. In turn, some practitioners of participation in R&I have called into question the actual usefulness of research ethics committees and the ethics review (Ashcroft, 2003; Lake & Wendland, 2018; Miller & Bolton, 2007). Simultaneously, a plethora of non-binding recommendations, values and principles to ensure the quality of co-creative processes has been developed both in gray and peer-reviewed literature (see e.g. Kieslinger *et al.*, 2022; OECD, 2022; Scher *et al.*, 2023). Still, none of the existing domain-specific guidelines and codes of conduct cover the sphere of research funding agencies, which operate at the intersection of science and policy, and currently mostly lack any ethical oversight when implementing participatory activities. As such, the experiences outlined in this paper serve to fill an important gap by providing insights into the ethics of stakeholder engagement and possible governance approaches in the context of research funding agencies.

The case of research funding agencies

The research funding agencies that were the subject of PRO-Ethics are government-funded institutions whose mission and mandate are clearly defined by laws and directives. Such organizations might act on a regional, national or international basis, and their strategic and programmatic orientation is determined in close conversation with the governmental institutions providing budget to these institutions (e.g. municipalities, ministries, the EC's Directorate General for Research and Innovation). Some of them provide funding to basic and/or applied R&I in the broadest sense, while others are focused on a specific domain, such as health research. (Aagaard *et al.*, 2021; Hydén, 2016; Thelwall *et al.*, 2023) Figure 1 was developed in the context of PRO-Ethics in conversation with representatives of the funding agencies involved in the project. It gives an overview of the processes implemented by the RFOs as part of its core business in the form of a research and innovation funding cycle, outlining the following key steps:

This funding cycle broadly starts with **strategy development**, which is the development of multi-year thematic R&I priorities which is usually done by funding agencies together with experts and ministries. From these strategic agendas, **funding programs are developed**, often still involving ministries to some degree, and attended to by program managers. Within funding programs, **topics for funding calls are identified and expanded upon**. Through these areas of responsibility, funding agencies are involved in determining the scope and potential impacts of research. In the latter step of the process, we also situate what we call 'proactive program management', which entails certain services provided by some funding agencies, such as providing consultation and training for (potential) beneficiaries and organizing capacity building workshops and matchmaking activities.

After calls are launched, the next step is the **evaluation of proposals** and the selection of projects for funding, which might also include an initial ethics review procedure. From there, **selected projects are implemented and monitored**, which entails administration and reporting procedures. Some funding agencies might also offer some form of mentoring or training as part of this step or integrate such activities in their funding instruments – asking, for instance, for such activities to be included in project plans. In a final step, **projects and funding programs are evaluated and their potential impacts are assessed**. The results of these evaluations feed back into the development of strategic agendas, funding programs and calls.

This R&I funding cycle represents a broad approximation of the core business of RFOs, as there is great diversity in how funding agencies operate, depending on the sectoral, cultural and legal specificities they operate in. As such, some steps might take more weight in the internal processes of an agency than others, and some might even be skipped entirely. Nevertheless, the R&I funding cycle helps illustrate how funding

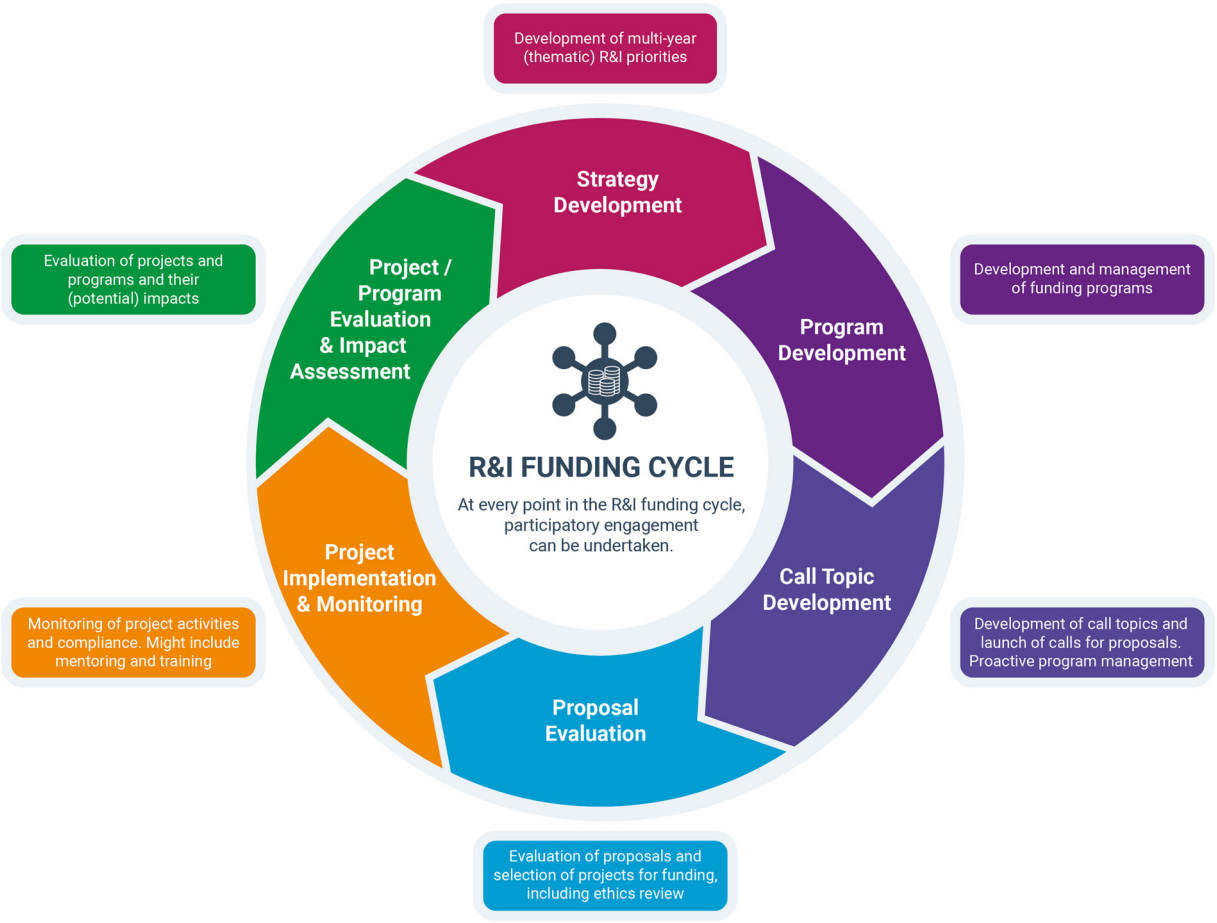

Figure 1. The R&I Funding Cycle. This figure has been reproduced with permission from Schuerz, Stefanie (2023): Research and Innovation Funding Cycle. DOI: 10.5281/zenodo.8096861.

agencies might open themselves up to participation, as outside stakeholders might be engaged in some way or another throughout the entirety of the process. Reasons for involving various publics in the activities of funding agencies largely overlap with those outlined in the introduction of this paper, with the added benefit of involving stakeholders in the decision of which topics are worthy of receiving funding.

While RFOs can invite stakeholder participation throughout the entirety of the research funding cycle, it is important to note that there are different depths at which participation can be implemented. Figure 2 was inspired by a number of papers, including Arnstein (1969); Kaisler & Missbach (2019) and Berditchevskaia *et al.* (2021). It proposes a spectrum of stakeholder empowerment depending on the decision-making powers afforded to participants. It starts with the mostly one-way **informing** of various publics, where no input is collected, e.g. via newsletters, press releases, or public information events. In public **consultations**, which might take place via a citizen forum or survey, participant input on a topic is collected, but no guarantee is given that this will affect a process and its outcomes. This might e.g. be done to collect the experiential knowledge of citizens on a specific call topic.

Involving pertains to a short-term participation in a process that affords limited decision-making power. An example for this would be one or several workshops implemented with citizens to involve them in the definition of strategic agendas or funding programs. **Collaboration** goes a step further and involves multiple steps, active involvement in decision-making, and an interaction of professional and lay stakeholders. An example of this would be citizen advisory boards that collaborate with scientific advisory boards on proposal reviews and might be involved in the mid-term and final project evaluation. The final step of **co-creation** pertains to a comprehensive collaboration between stakeholders from beginning to end, e.g. from the identification of relevant topics and the development of a funding program up to its evaluation.

While the terms employed in the graph do not mean the same in every context of application[2], they still demonstrate how participatory engagement is not monolithic, and the level of

[2] Co-creation specifically overlaps here with the concept of co-production (Bandola-Gill *et al.*, 2023), while the term also has a rich history of use in economic contexts (Voorberg *et al.*, 2015).

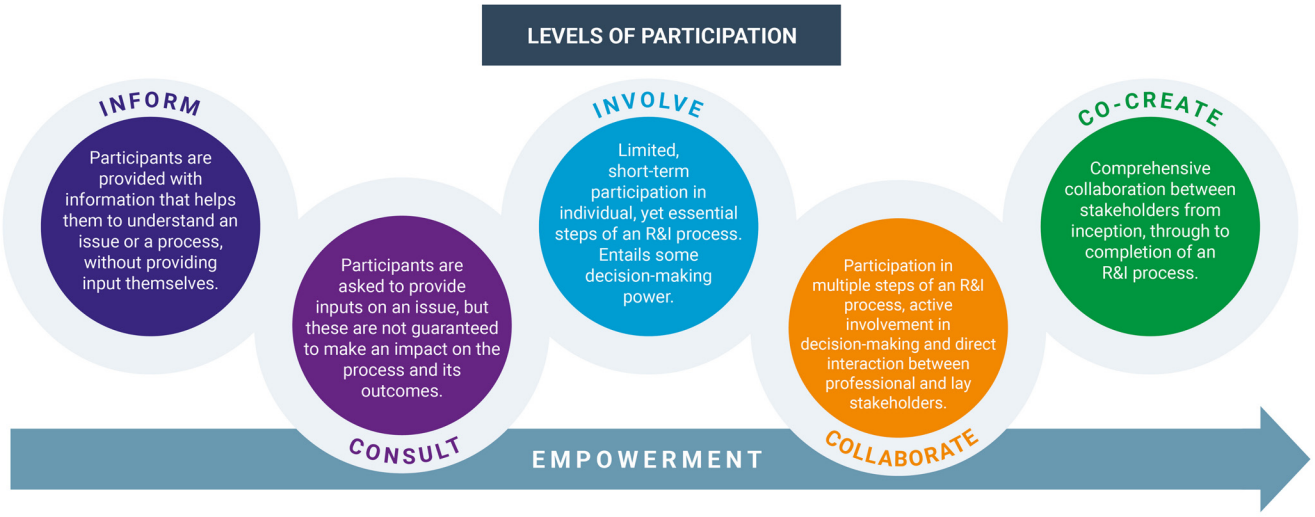

Figure 2. Levels of Participation. This figure has been reproduced with permission from Schuerz, Stefanie (2023): Levels of Participation in Research and Innovation. DOI: 10.5281/zenodo.8096864.

participation is dependent on the objective of the participatory exercise. It is also important to point out that the format of participation does not automatically define the degree of empowerment given to participants, as inputs can be disregarded even with quite involved methods of engagement. The following sections will outline the experimental setup within which participatory engagement in the activities of RFOs was tested and discuss in depth the learnings drawn from this process.

Contextual setting: 11 participatory pilots

The present paper builds on the work done over four years in the context of the European funded project PRO-Ethics. The primary objectives of PRO-Ethics were to gain a better understanding of ethical issues arising when research funding organizations (RFOs) engage broader stakeholder groups in their activities, and to develop recommendations for the organization, implementation and evaluation of participatory processes in the form of an ethics framework and guidelines (see Wiarda *et al.,* 2023a). The consortium was made up of funding agencies, international expert organizations and technical partners from across Europe. An advisory board made up of four experts on citizen science, research integrity, and gender and inclusivity was actively engaged with the project throughout its runtime.

To achieve our goals, we collected empirical data via a variety of formats. Most importantly, the RFO partners of PRO-Ethics implemented *eleven experimental pilots*[3] in which well-defined activities all along the R&I research cycle were opened up to 'non-traditional stakeholders'. While stakeholders were defined as any individual or organization with a stake in a process (i.e. either affected by the process or affecting it themselves), the term 'non-traditional stakeholders' was chosen to refer to all stakeholder groups not usually included by funding agencies in their activities. Depending on the thematic focus and the goals of the process at hand, these entailed, among others, citizens in the broadest sense (as in residents of an area or a country); end-users of a technology to be developed via R&I projects (such as assistant technologies for older people or informal caregivers); people affected by an issue (such as unhoused people or people with chronic fatigue syndrome and their relatives); entrepreneurs; project beneficiaries; NGOs; and civil society organizations[4].

Similarly, within these pilots a variety of engagement formats were implemented to engage with stakeholders, covering a large variety of methodologies and intensities of collaborations. Table 1 below gives an overview of the eleven pilots, including the RFO process targeted by each pilot, its thematic focus, the involved stakeholder groups, and the employed formats:

The RFO partners entailed national and regional research and innovation funding agencies from Austria, the Czech Republic, Germany, Lithuania, Norway, Romania, Spain, and the

[3] The pilots were implemented in two phases. While the pilots of phase two were developed and implemented in the project runtime, the pilots of phase one were already ongoing activities by four of the RFO partners of PRO-Ethics. Learnings were extracted both through individual reflection as well as bi- and multilateral reflection formats.

[4] As might be apparent from these examples, these categories are not entirely clear-cut, but may indeed overlap, with participants potentially inhabiting several roles – consecutively or at once – over the course of a participatory process. This in turn has ramifications for the collaboration that need to be carefully considered from the very beginning, as will be discussed later in this paper.

Table 1. Overview of PRO-Ethics pilots.

	Country	Target process	Thematic focus	Participants / stakeholders	Employed formats
1	Austria	Participation in R&I projects	ICT-based solutions to increase the quality of life for older adults	Technology end-users and other relevant stakeholders (e.g., service providers, NGOs, interest groups)	Various (chosen by project implementers)
2	Germany	Participation in topic identification and program design	Ethical, legal and social implications of new and emerging technologies	Technology end-users of various kinds and other relevant stakeholders, incl. ethic boards	Various (chosen by project implementers)
3	Norway	Systematic pre-call consulting	Research topic definition to address chronic fatigue syndrome (ME/CFS)	Patients and their relatives, patient/user organizations, health authorities, researchers	User panel
4	Belgium	Participation in project / proposal evaluation	Increasing the resiliency of the Brussels Capital Region (BRC)	Residents of the BRC	Citizen jury
5	Germany	Participation in project/ proposal evaluation and project implementation	ICT-based solutions for informal caregivers	Informal caregivers, interest groups, NGOs, researchers, ministry representatives	Citizen advisory board
6	Norway	Participation in capacity building	Citizen participation learning hub	Researchers, public and private sector institutions, civil society organizations	Peer-learning workshops
7	Austria	Participation in topic definition	Preparing funding call topics at the interface of health and climate change	Residents of Austria, researchers, practitioners, scientific experts, ministry representatives	Online survey, validation workshop
8	Belgium	Participation in thematic definition of program calls	Prioritize challenges from the Regional Research and Innovation Strategies for Smart Specialization (RIS3)	Residents of the BRC	Online survey, citizen atelier workshops
9	Romania	Participation in strategy development	Defining and validating the Romanian National R&D Strategy 2021-2027	Residents of Romania	World café workshop
10	Spain	Participation in program evaluation	Social impact evaluation of the NEOTEC program	Program managers, industry representatives (incl. consulting firms), NGOs / interest groups, beneficiaries	Workshops, focus groups, interviews, survey
11	Austria	Participation in topic identification, capacity building	Healthcare needs of (formerly) unhoused people	(Formerly) unhoused people, NGOs, interest groups, researchers, etc.	Focus groups, outreach activities
	Czech Republic	*Participation in project/ proposal evaluation*	*Involving stakeholders in the program committee of the ZÉTA program*	*Program beneficiaries with different professional and sectoral associations (researchers up to 35)*	*Pilot terminated*[5]

[5] The pilot implementing partner had planned its activities in the context of an SSH funding program, which could in the end not be implemented due to insufficient funds. As a consequence, the pilot had to be terminated.

Brussels Capital Region (BCR). There was a considerable variety among them regarding their geographic, programmatic and financial scope, their leverage within their respective national R&I ecosystem – including how accepted stakeholder engagement in R&I already is as a methodology – and their relationships with their respective funding ministries, including their leeway for structuring internal processes. To account for these differences, pilots were developed in a highly targeted manner taking any particularities into account.

The pilot implementing partners received support in the form of training, dedicated peer-learning formats, and targeted

feedback by both the technical partners and the project advisory board. Through the pilots, experiential knowledge on participatory engagement in the context of RFOs was built, while the practicalities and ethical challenges of opening up RFO processes were explored. To maximize learning potential, the pilots were implemented in two phases, with extensive bi- and multilateral reflection taking place within each cycle. In addition, multiple workshops with external stakeholder groups – including policy makers, funding agencies, research ethics committees (RECs), research integrity organizations (RIOs), and citizen science practitioners – were implemented to discuss results, collect further inputs and perspectives, and to validate project findings.

Methods

Data, methodology and guiding question

The project partners relied on a variety of reporting formats for data collection. The work done in both internal and external workshops was documented, with some being recorded and transcribed for in-depth analysis. As most of the project took place during the Covid-19 pandemic, online whiteboards were an important tool to collect inputs in a structured manner, while the few in-person workshops implemented mostly drew on flipcharts. Meeting notes and transcripts of important narrative observations were also produced by project partners.

For the first pilot phase, which drew on existing initiatives within four funding partner organizations, a structured reporting and assessment template was developed by the team at ZSI with the purpose of streamlining the RFO partners' reflection process[6]. In pilot phase two, this approach was both deepened and broadened through the deployment of continuous reporting formats. On the one hand, a template for activity reports collected general data on each activity, such as the number and types of participants, the goals of an activity, and the specifics of the recruitment process and engagement formats. The report also prompted a reflection on encountered challenges, the results of activities, and the first draft of the Ethics Framework and Guidelines[7], which was to be tested and validated via the phase two pilots. Towards the end of the project, pilot partners were further asked to provide a final pilot summary following a common template[8]. On the other hand, narrative 'pilot stories' were collected from all pilot partners to provide additional context and information, and to enable a better understanding of the activities. The template employed for this provided an opportunity to share narrativized reflections on pilot activities beyond the PRO-Ethics consortium, while allowing space for confidential reflections with a field collecting comments for internal use only[9]. This more individual reporting process was complemented by three cross-pilot learning workshops, four general assembly meetings, as well as regular exchange meetings, allowing for extensive documentation and status updates on the pilots.

The data were collected by various project partners and shared both in raw form and as reports, all of which were textual. They were organized by the authors of this paper and evaluated according to their applicability to the guiding question of the project and hence of this paper: *What are the drivers and barriers to ethical participatory processes in the context of RFO activities?* To elicit the particularities of funding agencies as implementers of participatory processes, a special focus was put on *(governance) structures and their impact on the ethics of participation.* After pre-structuring the data and excluding those deemed irrelevant to the question at hand, the remaining data were analyzed in their entirety in a qualitative content analysis following Mayring (2014, 2019). Transcription systems ranged from comprehensive protocols (summing up key content) to pure verbatim protocols (including utterances like "uh" and "um"), depending on the context and concrete goal of data elicitation within the project. Drawing mostly on a systematic coding of text material, the qualitative interpretation of data took place both in a deductive way – according to codes developed through the research question and expanded by the codes already included in the reporting templates – and inductively as categories emerged from the data material. The resulting codes were systematically re-checked by actively looking for alternative readings and contradictive evidence in the data. Results were critically discussed with project colleagues and reviewed by the pilot partners.

Analysis

The experiential data collected throughout the project shows a lot of similarities between stakeholder engagement in RFO activities and participatory practices across the science system as outlined above. On the one hand, the RFO partners of PRO-Ethics mention a number of motivations, aspirations and visions of the potential benefits connected to their participatory endeavors, which also serve to justify the considerable efforts invested by the teams into their pilots. These are often in line with the expected benefits outlined in the introduction of this paper and include: gaining insights into the (urgent) needs of (underserved) communities and thus filling knowledge gaps; developing internal expertise on participation; contributing to the opening up of science and strengthening collaboration between policy, society and science; but also, developing new and more relevant funding programs, training formats, and research networks; developing clearer guidelines for ethical participatory engagement in the organization and in funded projects; and creating benefits for projects, improve their overall quality,

[6] The reporting template and evaluation results for pilot phase one can be found in the project deliverable: Schrammel, M., Schuerz, S., & Sturn, D. (2021). PRO-Ethics D2.1 Summary and evaluation on Pilot I results. Zenodo. https://doi.org/10.5281/zenodo.4494369

[7] The final version of this document can be found here: Wiarda, M., Giannelos, K., Schuerz, S., Reber, B. & Doorn, N. (2023). Ethics Framework and Guidelines for Participatory Processes in the Activities of Research Funding Organizations. Zenodo. https://doi.org/10.5281/zenodo.8089672

[8] For further information, see Schuerz, S., Fetting, C., & Shiroka, S. (2024). PRO-Ethics D2.4 Reports on Pilot II Results. Zenodo. https://doi.org/10.5281/zenodo.10677184

[9] For further information, see Alves, E. (2024). PRO-Ethics D3.5 Synthesis report on pilot experiences. Zenodo. https://doi.org/10.5281/zenodo.10677197

foster societal debate, and enable better democratic legitimization and transparency of the funding process. As such, existing rationales for public engagement in R&I still seem to be valid even when broadening the scope of participation to RFOs.

Similarly, many of the recommendations, values and principles developed in this sphere remain applicable (such as the previously mentioned OECD, 2022, Kieslinger *et al.*, 2022, Scher *et al.*, 2023). At the same time, the following analysis exposes significant points of tension with the broader principles of research ethics and shows the practical challenges of safeguarding ethics in complex multi-stakeholder processes. These are heightened by the fact that funding agencies operate at the intersection of science and policy, leading to fundamental structural differences to be addressed when planning, implementing and evaluating participatory activities in this context. Contrasting the theoretical considerations of previous chapters with the realities encountered in the PRO-Ethics pilots, the following section discusses the specificities of (ethical) engagement in RFO activities as elicited from our data along three axes: 1) structures, in terms of how funding agencies must proactively lay the groundwork for enabling ethical participatory processes; 2) processes, especially in terms of managing the different steps involved in recruiting and engaging participants; and 3) actors, in terms of the roles and responsibilities the involved stakeholders may inhabit.

Structures: Laying the groundwork for ethical participation

"Reflecting the situation of funding agencies, where you have to strive for practical and working outcomes and results, and you have a limited resource base in terms of financing for those and in terms of staff resources, participatory approaches need to be a bit pragmatic." (Sabine Mayer, FFG)

Regardless of the context of their implementation, **participatory processes are very costly**, especially in terms of the time and resources needed to meaningfully bring together the wants and needs of often vastly different stakeholder groups. This is especially true when new participatory processes are to be set up in contexts where this is not traditionally done. For the funding agencies involved in PRO-Ethics, we found that the **national political and social attitudes towards participation**, and the subsequent willingness to support experimental participatory pilots, were an important factor impacting their activities. As taxpayer-funded national and regional RFOs operate in service of the public, they are underwritten by more or less restrictive **laws and regulatory frameworks** that determine a funding agency's **level of autonomy**. The pilot teams expressed many differences in terms of how much freedom their RFOs receive within their regulatory ecosystem to make decisions on thematic programming, internal budget-allocation, and the ways their daily business is implemented. Some legal and institutional frameworks, for instance, make it very hard for lay citizens to be involved in RFO processes at all.

"The legal and institutional framework presented a problem. Without changes, it would be impossible to implement many alternative participatory approaches as seen in other pilots (e.g. consulting long-term strategy, involving citizens in design of funding programs etc.). Particularly the legal changes required to implement the desired changes were not achievable in the given time framework (legislative changes of the respective laws and normative acts)." (Luboš Studený, TACR)

Thematic priorities are usually determined in collaboration with the ministries providing funding, including the budgets allocated to certain topics. Rules are also subject to change, as are funding streams, which sometimes further depend on international regulation. Depending on such factors, most pilot partners needed to lay a lot of groundwork in the runup to new activities to ensure **commitment from policy makers, institutional decision makers, and colleagues at the implementation level**, making time a factor from the get-go. On the other hand, the German case received unexpected support as an impetus for piloting participatory practices came directly from policy, paving the way from the top down[10]. While implementing the participatory pilots took a lot of preparatory work in terms of convincing different stakeholders and adjusting processes, the **daily business** of the funding agencies had to be maintained. This entails established processes with very tight deadlines – to develop funding programs, launch calls, choose projects for funding, etc. – and by itself already involves a lot of internal and external stakeholders. As such, any engaged participants represent an added layer of complexity.

While the pilot partners invested heavily in identifying how processes needed to be adapted, some challenges only unfurled over time. Downstream effects of new interaction modes were not always apparent, and unforeseen effects led to a need for adjustment on shorter notice further down the line. Some adaptations were also easier done than others, especially those with a lot of contingencies. As such, the RFO teams encountered various difficulties e.g. in cases where other programs were affected, regulatory systems beyond the organization were involved, where approval from ministries, research councils, or even changes in law were needed, or complex systems of compliance had to be set up. In such instances it became very difficult for the implementing teams to be responsive to challenges and stakeholder needs as they arose in the implementation of the process.

The **budgetary cover** of funding agencies also plays a role as a factor potentially exacerbating structural constraints by directly impacting how much staff is available to work on new tasks, how much time said staff has to trial new processes and funding instruments, and whether **external expertise** can be drawn upon to support a new activity. Several pilots made the experience that general understaffing and overload on responsibilities made it harder to take on additional responsibilities, or **develop new skills and expertise needed for the ethical implementation** of participatory processes.

[10] The Germany Federal Ministry of Education and Research made the Science Year 2022 all about participation, and in this context provided additional funding for participatory R&I endeavors. See https://www.wissenschaftsjahr.de/2022/english.html (accessed 20.12.2023).

"Now we are in the exploratory stage of mapping and choosing relevant stakeholders for internal workshops [...]. This is difficult, because we are overworked, which is also one of the obstacles we defined at the cross-pilot learning workshop." (pilot partner, April 2022)

However, some partners have also described how structural constraints can have **positive effects** as well, as they can force an early concretization of the work plan and thus a clarification regarding the scope, goals, and expected impacts of a process. This helped teams to align their ambitions with the institutional realities of implementation and thus mitigate a variety of risks, including overburdening the implementing team, blowing the budget, and overpromising what can be achieved.

Finally, there might also be a significant difference in what can and cannot be done based on the scope of an RFO's mission and its mandate. A smaller funding agency found it had more leeway to develop new and experimental formats. Reasons for this include a more limited overall budget (for both programs and projects) and thematic focus, resulting in smaller, more focused projects involving fewer partners that can be more experimental. When organizations address more distinct audiences, they may cater to their needs in a more responsive manner (e.g. through training or tailored funding instruments). On the other end of the spectrum, an RFO team struggled with the feeling of having to implement a lighthouse initiative with a lot of ministry involvement, where future decisions rest on the success of their single pilot project. Such heightened pressure might also narrow the options available to an RFO and complicate the overall process, even though ministry support tied to lighthouse initiatives might in the first instance seem beneficial.

Processes: Managing recruitment and engagement

"For a small-scale project that decides on a theme for a call for projects, it is very challenging to reach all these groups and arouse their interest. Which layer do we really want to reach, through which method and how many citizens do we want to reach? For many people, innovation is a distant concept and not everyone sees the added value of participating in consultations where the results are not very concrete or immediately tangible." (Cédric Verstraete, Innoviris)

"Our primary input is the National Agenda for Research. It might be a bit difficult to make the participants understand and differentiate between the societal and community issues they face that can be tackled through research solutions, and those that can be easily resolved by political will by national or local authorities. So they have to make this distinction and come up with problems that find their solution through research." (Alexandra Roman, UEFISCDI)

As laid out above, **ethical participatory engagement is not possible without a clear understanding of the structural context** within which a participatory process will be developed and implemented. For the funding agencies involved in PRO-Ethics, it is at this point unclear what a truly bottom-up approach to participation would look like, akin to what Haklay (2013) dubbed "extreme citizen science". As a consequence, all participatory activities started with identifying the right process(es) to be opened up to participation, including the goals to be achieved with such an intervention and the level of participation that is possible and will yield the desired result. From there, relevant target groups, appropriate methodologies, and necessary budgets were identified in a **recursive process**, as each decision was somewhat contingent on the others.

When identifying stakeholder groups to be involved, the pilot partners found it important to explore the **appropriate scope of engagement**, especially in terms of the tensions between breadth and depth of engagement. As approaches geared towards collecting dense inputs are more resource-intensive, this put a hard limit on how many activities could be undertaken, and how many people with differing subject positions could be involved. This in turn raised the stakes on the choice of participants, according to which criteria they should be selected, and whom they are intended to represent. For some partners, a **diversity of voices** was to be captured, which meant they had to clarify what axes of diversity could and should be taken into consideration, and how these would in turn be accommodated. By way of example, people with care duties have different needs from people with disabilities or those not fluent in the working language of a process[11]. To allow for meaningful participation, **barriers to participation had to be identified and addressed** for each target group, which is a potentially costly endeavor and could thus only be achieved in a limited manner within each pilot. Furthermore, the pilot partners also found significant differences even when working with relatively small populations, such as steep **hierarchies and power-imbalances** that were based on unforeseen categories of difference. This was even more true when different stakeholder groups and epistemic cultures were brought together in a context that traditionally favors one over the other:

"Our worries were if you just include the experts from the starting steps, they might just be biased towards their own contributions and reject inputs from citizens." (Sabine Mayer, FFG)

For certain tasks of a participatory activity, some pilot partners found it helpful to engage external support. This included **professional facilitation** to help address such tensions as mentioned above, as well as **recruitment agencies** to help engage a stratified sample of citizens according to predetermined criteria. Some partners made a conscious decision early on to draw on expertise from outside the organization, e.g. to alleviate time constraints and to supplement missing experience within the pilot implementing teams. In all such cases, this was positively remarked upon and seemed to help smoothen the overall process.

[11] The project partners focusing on vulnerable populations found that their ethical participatory process benefitted from approaching participant identities from an intersectional perspective, as they discovered hidden relationships of privilege and discrimination at play, beyond the presumably shared markers of (dis-)advantage.

Overall, engagement formats and facilitation techniques were carefully geared towards **managing the different expectations, needs, and capacities** brought to the table by different participants. As our funding partners themselves have to adhere to strict regulatory frameworks, they had to carefully consider the question of how open a process could and should be for the participants to shape. For instance, there was little to no leeway to adjust the goals and formats of a process in conversation with participants. This made it even more important to seek clarity on the stipulations under which participatory activities may take place and secure a clear commitment from decision makers to **respect stakeholder contributions** and give them at least some decision-making power – although this process was in the end not always successful. In any case, the conditions of participation were communicated in a **transparent** manner in order to avoid overpromising and subsequently undermining participants' trust in the RFO – and in turn in the science system overall. As one program manager puts it:

"We are aware that the fact that we are known as a funding agency might raise expectations among experts and citizens that are approached by us. This is potentially also a field of tension and might to some extent also influence the results of the study." (Gerda Geyer, FFG)

Actors: Negotiating roles and responsibilities

"I think the challenge for equal integration of the participants into the decision-making process, although some of them have less resources, is to give them the same role and the same responsibilities and the same power, so to say, to decide as the other members who maybe have more resources to begin with." (Markus Gerold, VDI/VDE-IT)

When planning and implementing participatory activities, the roles and responsibilities of involved actors were not always easy to define, communicate, and stick with throughout the process. Many pilot teams reported that they themselves experienced **overlapping and unclear roles**, as they had to keep a process steering towards certain predefined targets, remaining within certain thematic boundaries and within a certain scope (e.g. of time and resources), keep the quality of the process within academic standards, and take care of interpersonal and group dynamics of which they were very much a part themselves. On top of this, some partners had to **negotiate with decision makers on various levels** or did not themselves have the freedom to make choices on certain aspects of the process. This muddled set-up was at times perceived as overwhelming while it also risked negatively impacting the overall quality of the process, leading e.g. to pivots late in the process that in turn were a struggle to sufficiently accommodate. The following quote illustrates how precarious the position of funding agencies can be when they try their hand at participatory engagement:

"In this respect, the process was complicated by the fact that the online recruitment campaign had to be taken offline early, due to the inclusion of quotes that were considered too sensitive from a political perspective." (Cédric Verstraete, Innoviris)

Following this intervention, the pilot had to change its approach from online to street recruiting, which in turn led to a disappointing turnout for their follow-up activities. This points towards the **intrinsic motivation of participants** to engage with the process as a significant factor of success. Additionally, a broad **agreement between implementers and participants** on the roles and goals of the process needed to be secured. This, in turn, became difficult in one instance where participants found their identities as "experts-by-experience" – for which they were invited – less important than their professional identities – which they felt gave them authority to make decisions over aspects of a process they were not intended to evaluate or contribute to. This might generally be a dimension to be wary of when implementing transdisciplinary processes, where stakeholders have a claim to authority in a specific field that cannot be easily translated to another.

Overall, most pilots succeeded in defining and communicating the roles and responsibilities of participants in a clear and transparent manner. Nevertheless, issues arose in one pilot following different understandings of roles and goals among participants and within the wider community of stakeholders, which led to **exacerbating frictions**. One key aspect of this conflict lay in the different intensities with which some participants wanted to engage in the process, which was generally built to accommodate the time schedules of the most disadvantaged members of the group. One part of the group pushed from the very beginning to broaden their involvement, which led to these individuals gaining a stronger voice. This illustrates how **power imbalances must be actively countered** not just between different stakeholder groups, but also within ostensibly similar groups where differences in resources, capacity, goals and motivations can put immense stress on a process and disincentivize 'weaker' members of the group from continuing their participation. This is especially true for our funding agencies where a (re-)negotiation of roles and responsibilities or an adjustment of the overall process and its goals was much less possible than it usually is in participatory R&I projects.

To a degree, this topic overlaps with the question of **conflicts of interest**. Generally speaking, participants were not asked to join the pilot processes as entirely disinterested parties. Their interests were an integral part of why they were engaged, after all. However, some people did indeed bring their own very strong agenda to the table that came into conflict with the explicit goals of a process. Here, **expectation management** became an important factor, as there was a need to carefully harmonize what was sought in terms of goals and achievements, what was possible and feasible, and what was felt as a necessity on the side of the various involved stakeholders.

As such, continuously establishing clarity on roles and responsibilities, ensuring not to overburden individual actors, and including the expertise of outside experts (such as facilitators) where necessary became essential components of ethically managing and implementing the participatory pilot processes. In this context, a proactive reflection of potentially detrimental **internalized biases** and of **unknown unknowns** – potentially drawing on outside feedback and support – was important.

Pilot teams made an effort to understand their target groups by **engaging experts and expert organizations**, while actively exploring what could and could not be asked from citizens, and how much preparation (e.g. by adapting information material or compensation processes) might be needed to allow for meaningful participation.

Finally, one key question that had to be answered for all participatory activities undertaken by RFOs pertained to the **governance of ethics**. Who is responsible for safeguarding the ethics and overall quality of the process, what instruments can be leveraged to this end, and who is accountable to whom in this respect – especially in cases where the implementers of a process have little to no influence on the structural conditions of implementation? As one pilot partner put it:

"The setting that we are in, what should be done by us or by the people that we involve and what should be the responsibility of [...] the research ethics committees. It's not our job actually, you know, to make sure that research is carried out ethically, but we have a co-responsibility. So I think there are some interesting [questions]." (Anne Winsnes Rødland, RCN)

While there is not a singular answer to the questions laid out above, **responsibilities for ethical conduct must be clearly spelled out** in order to ensure that participatory processes are implemented in a manner beneficial to all involved stakeholders. Some possible instruments to that effect will be outlined in the conclusions of this paper.

Discussion

"The processes we are trying to apply and develop, learning by doing, adapting, and so on, we should also take that into consideration. We want to give good examples to agencies to embrace stakeholder processes in the future. We would have better chances of success if we can show the outcomes as well." (Gerda Geyer, FFG)

This paper outlined important approaches to research ethics and its governance before showcasing some of the complexities of (research) ethical conduct and decision-making when implementing participatory processes in the activities of research funding agencies (RFOs). While the ethics of participation in R&I are still rather theoretical and operationalized at a high level of abstraction (see e.g. OECD, 2022), our analysis shows the many challenges of translating them into practice, particularly for RFOs. A significant factor in this are **structural constraints** encountered by funding agencies. Due to their role as institutions operating at the intersection of science and policy, they are governed by often highly restrictive legal and institutional frameworks that can limit their freedom to implement participatory processes. As such, activities must be implemented while upholding the core business of the agency, leading to resources in terms of time, money and staff also representing an important structural challenge. Still, the need to concretize work plans early on in order to align ambitions with institutional realities and the subsequent clarification of process scope, goals and expected impacts is beneficial for the implementation of effective participatory activities. In terms of **processes**, managing the breadth and depth of engagement, identifying and addressing barriers to participation, and dealing with unforeseen categories of difference among stakeholders were encountered as challenges to ethical participation. Choosing an appropriate and feasible scope of engagement, proactively managing stakeholder expectations, and engaging external support and professional facilitation where necessary can help address tensions and improve the overall process. Regarding the **actors** involved in a participatory process, it was sometimes challenging to clearly define and transparently communicate their roles and responsibilities, which impacted the interpersonal dynamics. Decision-makers were not always easy to negotiate with, especially when strongly involved as key stakeholders in the process themselves. As such, proactive conversations on roles and responsibilities proved crucial for ethically managing participatory processes. In this, the importance of not overburdening individuals also became apparent.

While all eleven pilot processes were extremely well planned out, challenges arose in each pilot along the way – although some were more severe than others. Of particular note is that the pilot partners encountered a number of **ethical conundrums** where they were unable to find clear-cut answers for addressing them. Most prominent were struggles on **how to handle privacy, including in terms of legal compliance (such as mandated by the GDPR)**, e.g. when a deep thematic exchange is sought on a health research topic directly affecting participants. Furthermore, when trying to address the most pressing issues of our time, participants might be invited who experience stress and suffer due to the topic they are asked to contribute to. This in turn might lead to difficult dynamics between professional experts and experts-by-experience, as the **differences in epistemic culture** are harder to mediate when strong emotions are involved. In such cases, making sure not to unduly raise any hopes or overpromise on outcomes might become a challenge in itself. Another exacerbating factor in this context is that **those most affected by a societal issue might actually struggle the most to contribute**. By way of example, people who provide informal care to a sick relative often do this on top of paid work – meaning they have little free time – or instead of paid work – meaning they are in a financially precarious position. In both cases, it is important not to put undue burden on them, especially if the impact of their contributions might in the end be negligible due e.g. to structural constraints hindering truly participatory decision-making processes.

Returning to the ethical approaches outlined in the introduction, it becomes clear that all of them might provide some guiding principles to those responsible for planning, implementing and evaluating such activities. Within and beyond the pilot teams, ethical reflections were helpful in planning participatory processes and exploring practical solutions to arising problems. Following deontological ethics, we can indeed define some acts as right or wrong. For instance, our pilot partners took great care not to actively mislead participants about the level of participation possible in any given situation, or the mandate provided to an agency by decision makers. In teleological tradition,

they also looked at the downstream effects of participatory activities. They spoke of the challenges arising from insufficiently preparing and setting up participatory processes, which in turn leads to the risk of disenchanting all involved stakeholder groups on engagement efforts: Participants might leave such processes feeling that they could not meaningfully contribute or that the system of R&I project funding cannot provide meaningful results. Decision makers might similarly conclude that participation does not work and is not worth investing in. And implementing teams might find their efforts futile and not worth repeating. The pilot teams tried to proactively address these risks via proper planning and management of stakeholder expectations, yet could not foresee all tensions as they arose in the implementation of a process. This is where ethics of care became relevant for some partners, which look at ethical conduct as arising from relationships. Through this lens, we can see how difficult it is to accommodate the different wants and needs of all involved actors, which sometimes might actually be in competition with one another. Here, skillful and honest negotiation proved essential – but it also did not save facilitators from answering difficult questions on whose needs take preference.

Conclusion and outlook

Drawing on the lessons learned in our participatory pilots, we have identified a number of success factors, governance instruments and recommendations for the implementation of ethical stakeholder engagement in the field of research funding. Their concrete implementation needs to be explored both theoretically and practically, in terms of feasibility, appropriateness to the context, and effectiveness to meaningfully address ethical considerations of participation in the activities of research funding agencies.

Drivers of ethical engagement

First, a deep **understanding of the structural context conditions** must be developed and commitment from all relevant decision makers must be secured. All pilot partners agreed that **developing a friendly and mutually respectful atmosphere** where participants' time and inputs are valued was extremely beneficial to the successful implementation of their activities. This included efforts of **identifying and addressing barriers to participation**, amenities such as catering for on-site events, and in some cases **remuneration or compensation**, e.g. in the form of cash or vouchers, where this was possible. Here, again, legal and institutional rules and regulations might (dis-)allow certain compensatory schemes, depending in part also on the type of participant (for instance, project beneficiaries might not be allowed to receive payment beyond existing grants). In terms of engagement formats, choosing **dynamic and interesting activities** was also key to collecting rich inputs from participants.

Overall, **expectation management** came up repeatedly as an essential component for achieving a good collaboration. This entailed proper preparation as well as clear communication and transparency on all relevant information, including the goals of a process and the intended roles and responsibilities of participants. As people are asked to participate in contexts that are often far removed from their daily lives, care must be taken in how to structure information in order not to overwhelm participants – participants are, after all, invited to share their situated knowledge and lived experience, not to be schooled. In this respect, **informed consent procedures** were also experienced as a helpful instrument to create clarity on all sides.

Still, wherever possible, it is good to allow for a **responsive process design** in order to be able to adapt to the realities of the situation, including challenges and limitations that could not be anticipated. This includes **planning for feedback loops** and employing formative evaluation techniques to assess the activities while they evolve – including to actively collect feedback from participants in an appropriate format.

As stakeholder engagement is usually beyond the purview of funding organizations, special care must be put towards **team composition**, covering as much relevant expertise as possible within the organization, but also **engaging external expertise** wherever it is deemed necessary or helpful, including from external facilitators, recruitment experts and external ethics advisors. In addition, all pilot partners benefitted from **collaborating with relevant organizations** such as multiplier networks, expert organizations and interest groups. Many of these also serve as gatekeepers to communities. In any case, multipliers are better seen as important stakeholders to include, rather than purely opportunistically as communication nodes. By engaging such actors collaboratively, they are also less likely to turn into competitors in the attention economy, especially if many engagement activities try to recruit participants from the same target audience at the same time. Thus, a certain expertise in **multi-stakeholder engagement** is inherently beneficial to set up such processes effectively. And on a policy level, a clear driver of success is the **allocation of enough resources** and providing both a **mandate** and enough autonomy for the implementation of a participatory process that is responsive to the local conditions of implementation.

Despite meticulous preparation and reliance on a variety of internal and external resources, all eleven pilots encountered unexpected obstacles as well as positive surprises. There are many unforeseeable variables involved in participatory processes. One key learning from the pilots was that you need to **plan for contingencies and unexpected events**. For example, when there was a power imbalance between different participants in one of the pilots, the RFO needed to change their strategy in order to ensure an equitable process for all. This need for flexibility is also relevant in the context of ethics reviews, which have to accommodate for changing circumstances if they are to support different academic stakeholders in the governance of research ethics.

Scoping instruments for ethical governance

This finally brings us to the topic of **ethical governance of participatory engagement in the context of funding agencies**. A number of instruments might lend themselves to address

this issue, some of which have already proven themselves in the context of R&I projects:

- **Ethics self-assessment:** This would most likely take the form of a checklist, allowing the teams implementing a participatory activity to systematically set up their activities in a way that anticipates potential issues. One important drawback is that ethics should exactly not be treated like a box-ticking exercise confined to the beginning of a process, and must be responsive to an evolving situation. Still, such an instrument can be helpful at the planning phase and might also support intermediate evaluations.

- **Ethics review:** Actively engaging a qualified research ethics committee to review the planned process could be an effective mechanism of control to ensure ethical conduct also for funding agencies. Depending on the length and complexity of a participatory endeavor, such reviews might even be set not just at the beginning of a process, but also be incorporated in interim and end-evaluations.

- **External support:** RFOs might also benefit from engaging advisory boards, independent ethics advisors or ethics mentors to support their participation processes. In a similar vein, more continuous ethics support and counseling by RECs has been put forward as an approach to managing research ethics in times of increasing complexity.

In the closing of this chapter, we want to present our recommendations for funding agencies for how to approach participatory activities in order to safeguard ethical conduct.

Recommendations for funding agencies – and beyond

"In this case it was the least worst solution, but it is still not an ideal solution." (Steph Grohmann, LBG OISC)

- **Be aware that any decision you make will always be based on imperfect information.** Deciding on the right target group, appropriate recruitment and engagement formats, a realistic scope and ambitions, and meaningful goals can be very difficult, especially when this is a new process set up within existing structures unfamiliar with or even hostile to this form of activity. As such, ensuring that there is some flexibility to adjust the process along the way is essential. This includes to plan for regular timepoint for reflection and evaluation that support the dynamic adaptation and refinement of the participatory process.

- **Modulate your ambitions to the realities of the situation.** Choose the scope of your activity in conversation with the regulatory framework you operate in, the mandate and funding you were able to secure, the deadlines relevant to your activity, and the expertise available in your organization and in your team. RFOs operate in an exacerbation of the project logic, with tight deadlines, resources and budgets that are hard or impossible to move. If things go awry, there is not so much leeway to adjust or re-do activities. Too much ambition can negatively impact the process and might be in conflict with ethical considerations, as it is not good to include populations you then cannot properly cater to.

- **There is no perfect process.** At the same time, no process can be implemented in an entirely smooth and tension-free way. Challenges might arise that cannot be addressed in an entirely satisfactory way – for instance when reaching out to participants – while it sometimes is sufficient to find a solution that is "good enough". This is also true in terms of ethics, where the principle of minimizing harm might come before the principle of beneficence. This is also why cookbook approaches have limited value and experiential knowledge is of prime importance.

- **Plan ahead.** Nevertheless, it is important to plan ahead in terms of timeline, scope, available resources, potential (ethical) risks, and mitigation strategies. As a part of this, quality checks, reflection and evaluation, adaptation and refinement must be actively designed into the process. As part of this planning, it is also key to anticipate and find ways to actively address different stakeholder interests, expectations, and needs, including power imbalances within and beyond stakeholder groups. It is also helpful to have a plan B to fall back onto in case plans don't work out.

- **Build knowledge hubs / centers of expertise for ethical participation.** Such institutions would be responsible for developing expertise on ethical participation in R&I (funding). These can serve both as internal and external support structures that organize, implement and evaluate participatory processes, develop best practices, and offer training and capacity building to RFO and project staff alike. These excellence hubs can be internal to an RFO but can also be set up in collaboration with other R&I actors such as universities and other RPOs, RECs, RIOs, as well as ministries and other public institutions. In any case, RFOs would benefit from building long-term expertise and sustainable structures for engagement.

- **Engage external experts on ethics and participation where necessary and helpful.** It is important to be very clear-eyed on what can be realistically implemented relying on internal expertise alone. On principle, a participatory process should be implemented with at least one colleague on the team who has experience with such a process. This is an effective strategy of risk mitigation, as experience makes it much easier to anticipate frictions and develop solutions. Such expertise can, however, be external to the team.

- **Deal with failures constructively.** No participatory process can ever be implemented without friction. Experimental activities beyond the core business of an RFO are especially precarious, as national funding agencies are beholden to laws and policy decisions

in a much more immediate way than R&I projects. Such activities must be situated within existing processes that have to be implemented efficiently, both in terms of timelines and costs, and thus allow for little leeway. As such, adaptations in the form of sustainable institutional change must be sought in a cautious and iterative process, allowing RFOs to learn from the processes they implement. Mistakes will happen, activities will fail, and this allows for rich data to be collected on pain points of ethical participatory engagement in funding agencies. Do not throw the baby out with the bathwater.

Ethics and consent

The project underpinning this publication was a H2020 coordination and support action for the development of an Ethics Framework for funding agencies. All colleagues implementing pilots were funding agencies without access to research ethics committees. Instead, safeguards were put in place, including feedback loops with an independent advisory board that reviewed each partner's informed consent procedures as well as the overall pilot design and implementation. The Horizon Ethics Self Assessment was completed and the project stayed within the clauses of the Grant Agreement.

Since the PRO-Ethics pilots employed a great variety of engagement formats, informed consent procedures were tailored to the respective type of engagement. For more complex, in-depth or prolonged participation (such as interviews, focus groups, workshops, citizen jury and citizen advisory board), written informed consent was obtained from all participants. For contributions to online surveys and the online peer-learning hub, privacy statements were used informing participants of their rights as well as the management and handling of their data in compliance with relevant laws and institutional guidelines.

Data availability

All non-sensitive data associated with this publication are linked in their published form as Annexes to reports. Some of the data underlying these results cannot be shared due to confidentiality concerns and were classified in their dissemination level as "confidential". This designation is explicitly defined as "accessible only to members of the consortium (including the Commission Services)".

Researchers or reviewers interested in accessing further data may contact the corresponding author. Applications for data access should include a detailed explanation of the purposes and types of data processing planned. The corresponding author will assess each request individually, considering the relevance and purpose of the research. If approved, access will be granted under specific conditions, which may include agreements on data usage, confidentiality, and publication rights.

Acknowledgements

We would like to thank the PRO-Ethics Consortium and all involved actors for the extensive data collection, collaborative reflection and inspiring discussions contributing to this work. We want to extend our special thanks to Matimba Swana, Katja Mayer, Marius Oesterheld, and Claudia Fabó Cartas for their valuable feedback. A prior version of this paper has been submitted as a project deliverable.

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Open Peer Review

Current Peer Review Status: ? ? ?

Version 1

Reviewer Report 25 March 2025

https://doi.org/10.21956/openreseurope.20297.r51062

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Anne-Floor Scholvinck
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The article addresses an important gap in the current literature on PE; namely, how to involve 'non-traditional stakeholders' ethically in the processes of RFO's. It promises to provide insights and recommendations on ethical stakeholder participation at research funding agencies.

Whilst the paper covers a potentially rich dataset consisting of as many as 11 pilot projects, my main point of critique is that I feel the interpretation of the data could be more profound.

Firstly, the listed barriers and facilitators affecting PE at RFO's is thorough and recognizable. Yet, they diverge little from the extensively documented barriers and facilitating factors affecting PE in research practice, and are therefore not very surprising to readers who are well-versed in the topic of PE. Paying more attention to the challenges specifically RFO's face when involving non-traditional stakeholders, may make the results far more interesting. E.g., I can imagine recruiting sufficient participants for a funding process is even more challenging than finding participants in a research project, as funding research is yet another step beyond carrying out research, in terms of finding concrete solutions to stakeholders' issues. (This is just an hypothesis, I would be interested to see empirical evidence in this regard).

Secondly, delving deeper into the particularities of each pilot, and linking these to your various results, may also help to unveil more meaning from your data. As you show in Table 1, the 11 pilots varied on a number of factors, including the target process and the employed formats of PE. A (more systematic) analysis of how these factors relate to the experienced barriers and facilitators at the RFO's could also be helpful in providing more concrete recommendations.

Thirdly, the ethical lens through which the barriers and facilitators of PE at RFO's is analysed, seems rather thin and (in its current form) isn't of much added value to my understanding of the results. Deepening the analysis could be done by systematically applying a new, or existing, framework regarding ethical PE on the data. Inspiration for such a framework may be sought in the guiding principles of the 2021 UNESCO Recommendation on Open Science (Ref-1), or the recommendations, values and principles cited in your own introduction (Kieslinger *et al.*, 2022;

OECD, 2022; Scher *et al.*, 2023).

This lack of analytical depth takes its toll in the discussion section. Interpreting the data in terms of transition management literature (by Derk Loorbach c.s.) might be a fruitful avenue to take a step beyond plainly categorizing the observations. For example, the experienced structural constraints such as legal frameworks and lacking mandates clearly call for the need of transition arena's, in which niche practices such as PE at RFO's get sufficient freedom to experiment and learn-by-doing.

In addition to my suggestions above, I have two minor points of feedback;

- The barriers and facilitators listed in the article all seem very RFO-focused; did you also analyse the barriers and facilitators that the participants faced in the process of (not) being involved? Did you collect data amongst non-traditional stakeholders who were involved in the pilots? If not, this might be worth mentioning as a demarcation in the scope of the article.

- In the conclusion, some new information seems to pop up which (to me) doesn't follow logically from the results section. E.g. the issue of remuneration/compensation of the participants, team composition, and involving external expertise have not been discussed before.

Although the work presented as is, is sound and valid, I believe that one more iteration of interpreting and analysing your data could bring the paper much depth and meaning. With such a large and rich dataset resulting from 11 pilot projects, you could really provide novel insights in the governance of PE at RFO's, which the field desperately needs.

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Is the work clearly and accurately presented and does it engage with the current literature?
Yes

Is the study design appropriate and is the work technically sound?
Partly

Are sufficient details of methods and analysis provided to allow replication by others?
Partly

Are all the source data and materials underlying the results available?
Yes

If applicable, is the statistical analysis and its interpretation appropriate?
Not applicable

Are the conclusions drawn adequately supported by the results?
Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Public involvement in science

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 06 March 2025

https://doi.org/10.21956/openreseurope.20297.r51067

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Summary of the Article
This article investigates the ethical complexities of integrating participatory stakeholder engagement into the activities of research funding organizations (RFOs), drawing on empirical data from the EU-funded PRO-Ethics project. The study analyzes eleven pilot initiatives across European RFOs, exploring how these government-funded institutions can ethically involve non-traditional stakeholders (e.g., citizens, end-users, NGOs) in their research and innovation (R&I) funding cycles. The authors frame their analysis around three axes—structures, processes, and actors—highlighting drivers and barriers to ethical participation. The paper situates RFOs at the intersection of science and policy, arguing that their unique position amplifies ethical challenges compared to traditional R&I contexts. It concludes with practical recommendations and governance instruments (e.g., ethics self-assessment, external support) to enhance inclusivity and integrity in RFO participatory practices. The work is highly relevant to ongoing debates about Responsible Research and Innovation (RRI), open science, and public engagement, offering a novel focus on funding agencies rather than research projects themselves.

Relevance
The article addresses a timely and underexplored topic: the ethical governance of stakeholder participation in RFOs. As public engagement becomes a priority in European R&I policy (e.g., via Horizon Europe and RRI frameworks), understanding how funding agencies can adapt to these demands is critical. This study bridges a gap between theoretical ethics and practical implementation, providing actionable insights for RFOs navigating participatory processes within rigid institutional constraints. Its findings are particularly pertinent to policymakers, funding agencies, and researchers interested in democratizing science governance.

Overall Assessment
I approve this article for indexing due to its originality, empirical richness, and practical contributions. **However**, I have reservations about certain aspects that could be strengthened to enhance clarity, rigor, and utility. Below, I outline the strengths and weaknesses, organized into "Major" and "Minor" points, with suggestions for improvement.

Major Points

1. Strength: Empirical Depth and Novelty
The paper's strength lies in its detailed empirical foundation, derived from eleven diverse pilot studies across multiple European RFOs. This provides a robust dataset that captures real-world challenges and successes, making the findings credible and contextually grounded. The focus on RFOs as a site of participatory engagement is novel, extending existing literature on public participation in R&I (e.g., citizen science, transdisciplinary research) into an underexplored domain. The three-axis framework (structures, processes, actors) effectively organizes the analysis, offering a clear lens to dissect ethical complexities.

2. Weakness: Limited Engagement with Ethical Theory
While the introduction briefly outlines ethical approaches (e.g., deontological, teleological, ethics of care), the paper does not fully leverage these frameworks to analyze the pilot findings. For instance, the "ethics of care" is mentioned as relevant but not systematically applied to the data (e.g., how it could address power imbalances or emotional burdens on participants). This leaves the theoretical discussion somewhat detached from the empirical results, weakening the paper's ability to bridge theory and practice—a stated goal. I suggest integrating ethical theories more explicitly into the analysis section. For example, discuss how an ethics of care could guide responses to vulnerable participants (e.g., informal caregivers) or how teleological ethics informs the trade-offs between process costs and outcomes. This would strengthen the conceptual contribution and justify the theoretical framing.

3. Weakness: Ambiguity in Ethical Governance Instruments
The proposed governance instruments (ethics self-assessment, ethics review, external support) are promising but lack specificity. The paper critiques ethics reviews as static and biomedical in origin yet suggests their use without explaining how they should be adapted for RFO contexts. Similarly, "external support" is vague—does this mean ethics consultants, community liaisons, or something else? This ambiguity limits the practical utility of the recommendations. I suggest provide concrete examples or criteria for each instrument. For instance, outline what an RFO-specific ethics self-assessment checklist might include (e.g., questions on participant compensation, power dynamics) or specify the qualifications of external ethics advisors. This would make the recommendations more actionable.

Minor Points

1. Strength: Practical Recommendations
The recommendations (e.g., "Plan ahead," "Modulate ambitions," "Build knowledge hubs") are pragmatic and well-tailored to RFOs' operational realities, such as tight budgets and regulatory constraints. The emphasis on learning from failures and planning for contingencies is particularly valuable, reflecting a realistic approach to institutional change. These insights are likely to resonate with practitioners and inspire further experimentation.

2. Weakness: Insufficient Discussion of Pilot Variability
The paper mentions diversity among the eleven pilots (e.g., geographic scope, thematic focus) but does not explore how these differences influenced ethical challenges or outcomes. For

example, did smaller RFOs face fewer bureaucratic hurdles than larger ones? Did health-focused pilots encounter unique privacy issues compared to others? This omission reduces the generalizability of the findings. I suggest adding a brief subsection in the "Analysis" or "Discussion" comparing key differences across pilots (e.g., a table summarizing pilot characteristics and ethical issues). This would highlight context-specific lessons and strengthen the paper's applicability.

3. Weakness: Overuse of Quotations Without Synthesis
The "Analysis" section relies heavily on direct quotes from pilot partners, which, while vivid, sometimes overshadow the authors' own interpretation. For instance, quotes about structural constraints (e.g., Sabine Mayer, Luboš Studený) are compelling but not always followed by a clear synthesis of their broader implications. This risks leaving readers to interpret the data themselves. I suggest reducing the number of quotes and integrate them into a stronger narrative. After each quote, summarize its significance (e.g., "This highlights how legal rigidity can stifle innovation in participatory design") to guide readers and reinforce the authors' voice.

4. Strength: Accessibility via Plain Language Summary
The inclusion of a plain language summary is commendable, making the research accessible to non-experts, such as policymakers or community stakeholders. It effectively distills complex ideas into clear, relatable terms, aligning with the paper's ethos of inclusivity.

Is the work clearly and accurately presented and does it engage with the current literature?
Yes

Is the study design appropriate and is the work technically sound?
Yes

Are sufficient details of methods and analysis provided to allow replication by others?
Partly

Are all the source data and materials underlying the results available?
Partly

If applicable, is the statistical analysis and its interpretation appropriate?
Not applicable

Are the conclusions drawn adequately supported by the results?
Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Science of science, research policy

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 26 February 2025

https://doi.org/10.21956/openreseurope.20297.r51063

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Gerd Gigerenzer
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The article addresses an important issue, the participation of the public ("stakeholders") in research funding organizations. However, it often lacks clarity and needs to be improved in a number of respects.

1. No distinction is made between curiosity-driven research where researchers determine what topic they want to pursue (as funded by the European Research Council (ERC)) and mission-driven research (as funded by the rest of the Horizon Europe Program). If public participation entails determining topics of research (as the authors state on p. 7 and in Table 1), this participation is relevant solely for organizations that support mission-driven research, but not for funding organizations such as the ERC. In fact, the ERC has been struggling for years to maintain its independence and fend off numerous attempts of stakeholders to gain control over the topics being funded. The authors need to address this issue.
2. The public—in particular, laypeople—could be useful for certain domains (e.g., interactions between physicians and patients, as in value-based medicine) but unlikely to be useful for other domains, such as quantum physics. The issue of domain needs to be addressed.
3. It is unclear to me why stakeholders' participation is referred to as ethical throughout the manuscript. If, for instance, members of the public recommend research on homeopathy or on general artificial intelligence, why should we call this participation ethical? Given that any industry or organization is classified by the authors as a stakeholder, the term *ethical* becomes even more problematic. I suggest deleting all mentions of the word apart from when referring to ethics review panels (see next point).
4. The term *ethics* is appropriate when referring to the ethics review panels that evaluate the research proposals submitted to or granted by a funding agency. Yet I have my doubts about the authors' suggestion to hire external reviewers to determine whether a grant proposal is ethical. In my experience as a board member of one the largest funding agencies worldwide, hiring external reviewers was counterproductive. It delayed the time until proposals were finally granted because of the excessive number of red flags (sometimes over 50% of all proposals), which then occupied the reviewers and the agency over months to resolve the mass of mostly false alarms. The reason seems to be a conflict of interest. It is in the very interests of external experts, who are paid for their time, to slow down the process by trying to avoid any potential miss. Our grantees suffered because they could not start their research without clearance. Instead, a system of trust seems to be preferable, which risks a few misses and handles complaints the moment they occur.
5. Table 1 is informative. Figure 1 does not apply to the ERC and other funding agencies that provide researchers the freedom to determine the topic, as mentioned above.

6. Throughout the paper, the reader would benefit from the authors being more concrete. For instance, on p. 13, right-hand column, we learn that “most pilots succeeded in defining and communicating the roles and responsibilities of participants.” But what are these roles and responsibilities? Or on p. 11, line 5, the authors refer to “many of the recommendations, values and principles developed.” What are these?
7. At the end of the paper, I still do not understand what the authors mean by “ethical governance of participatory engagement” (p. 15, last section). I can relate this to the ethics review process of proposals, but not to most of the topics in Table 1, such as topic identification.
8. The majority of the recommendations for funding agencies (pp. 16-17), such as “Be aware that any decision you make will always be based on imperfect information,” “There is no perfect process,” and “Plan ahead,” border on the trivial. These should all be deleted. Alongside these are also a few concrete recommendations, such as “Engage external experts on ethics.” As mentioned, this is a highly problematic recommendation in my experience because conflicts of interests slow down the process of granting and may force grantees to delay the start of their research.
9. In general, the text is often repetitive and would benefit from radical shortening.
10. The Results section does not report any results, and the Conclusions section is very unspecific. Please rewrite.

Is the work clearly and accurately presented and does it engage with the current literature?
Yes

Is the study design appropriate and is the work technically sound?
Yes

Are sufficient details of methods and analysis provided to allow replication by others?
No

Are all the source data and materials underlying the results available?
Yes

If applicable, is the statistical analysis and its interpretation appropriate?
Not applicable

Are the conclusions drawn adequately supported by the results?
Partly

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.