Citizen participation in research and innovation : benefits, risks and conditions of an ethical approach

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CITIZEN PARTICIPATION IN RESEARCH AND INNOVATION: BENEFITS, RISKS AND CONDITIONS OF AN ETHICAL APPROACH

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1. Introduction

In the context of scientific and technological development, participatory practices (citizens and stakeholders) introduce new audiences that can be beneficial to research projects or evaluation processes, if they are accompanied by greater consideration of ethical issues, going beyond the mere assessment of *ethical compliance*.[*] Participatory practices can also

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involve simple consultations or fairly elaborate deliberative formats, going so far as exploring ethical pluralism at work, which complicates what the famous political philosopher John Rawls (1993) has called the difficulties of judgement. The meeting of ethics and participation, with exposure to the moral intuitions of non-ethicists, extends to this point, if quality deliberation is to be achieved. The contribution of an ethical participatory activity to research and innovation (R&I) can improve the overall quality and legitimacy of the R&I process. However, establishing adequate and qualitative participatory processes is not a new concern; more importantly, it is not self-evident, despite several attempts to frame and guide the participation of heterogeneous audiences of ordinary citizens accompanied by experts in evaluating innovations (Blok et al., 2015; Davidson, 1998; Fiorino, 1990; Rowe & Frewer, 2000, 2005; Slocum, 2003). It is even more difficult if such participation is to be responsible and ethical. Without appropriate guidance, it is difficult to navigate the variety of configurations of public participation in R&I and to ensure that the participatory process is appropriate, legitimate, and consistent with notions of responsibility, integrity, and accountability.

Beyond disciplinary boundaries, exploring the link between participation and ethical principles allows us to investigate the conditions in which research ethics committees (RECs) could benefit from ethical participatory practices. Indeed, the encounter between ethics as a specific domain and participation, in the context of R&I, can lead to a two-way virtuous circle. This article focuses on the conditions in which RECs can benefit from ethical participatory practices. Two hypotheses are explored here: the first is that participatory practices could add value to the current functioning of European regulatory bodies dealing with ethics, both in the evaluation of R&I processes involving participants and in the agency processes involving participants, if it is considered that ethical guidance should take place from the very beginning of R&I processes (Van den

Hoven, 2014). An *ethics framework* would provide guidance for the design, implementation, and evaluation of participatory practices whenever they might be useful. The second hypothesis is that the degree of connection and fit of these participatory practices with ethics is variable; therefore, the value added by these participatory practices is also variable. This has implications for the ethical quality of these participatory practices.

Both ethics and participation have multiple meanings, and RECs do not necessarily cover the whole spectrum of ethics but mainly ensure legal compliance (regulations). The adoption of an *ethics framework* for participatory practices will be explored here both from the point of view of standard ethical processes and from the point of view of contributing to the R&I processes themselves.[22]

2. Benefits and Risks of Participation in Research and Innovation

Public participation processes have become an ever-expanding field, with very different objectives: facing the shortcomings of expert-led governance, correcting democratic deficits in policy-making (Fung, 2009), strengthening the democratic fabric (Fagotto & Fung, 2014), effectively addressing moral disagreements in politics (Gutmann & Thompson, 2004), and empowering a broader social base (Stirling, 2005).

From the perspective of responsible research and innovation (RRI) and responsible innovation,[23] the concept of responsibility raises questions about the future direction we seek as a society (Owen & Pansera, 2019) and proposes a more responsive approach to major societal challenges (European Commission, 2014; Von Schomberg, 2013), through a

[22] This article extends the arguments presented by Giannelos and Reber (2022).

[23] RRI is a policy discourse that was initiated by the European Commission (Science and Society programme), while responsible innovation has academic roots.

broader understanding of responsibility to society or to stakeholders (Van de Poel & Sand, 2018). Responsible innovation is a way of dealing with radical uncertainty (Grinbaum & Groves, 2013), while public dialogue—or deliberation—can be seen as a process suitable for uncertain futures, such that decision-making has to cope with limited scientific knowledge, and the risk of serious and/or irreversible damage if certain assumptions prove to be correct (Reber, 2016). Thus, in line with responsible innovation, R&I processes are required to adhere to principles of sustainability, social desirability and ethical acceptability (Von Schomberg, 2013), and responsibility is distributed across a network of actors (Doorn, 2012; Stilgoe, 2013). In an approach rooted in responsible innovation, notions of democratic governance, responsiveness, and accountability are key concepts that invite ethical, inclusive deliberations, which would include broader perspectives in terms of audiences and stakeholders (Owen et al., 2012).

The introduction of new audiences into the expert environment of R&I creates *benefits*, but also *risks,* which we will discuss below. These risks arise when the principles of accountability and integrity are not sufficiently explored or defined and remain at the level of unwarranted assumptions.

The *benefits of participation* include the implementation of responsible research and innovation (and its six pillars: participation, ethics, governance, open science, science education, and gender), and the establishment of *public dialogue.* Responsible development of R&I involves addressing research, science, and technology developments through public dialogue, which serves four main purposes: gaining public acceptance, informing governance about the future societal consequences of R&I developments, making science and technology governance more accountable, and increasing public understanding to avoid tensions (Sykes & Macnaghten, 2013). However, there are still grey areas when it comes to

innovation processes that are more responsive to societal needs and values and able to anticipate societal uses and consequences (Van de Poel & Sand, 2018).

The introduction of new audiences also entails risks, particularly because of a sometimes limited understanding of and approach to ethics, leading to inappropriate participatory processes, a widening of the gap between government and the general public, a low added value of participation (which impacts its legitimacy and may even lead to cynicism in the case of broken promises), and finally, processes that reveal show structural weaknesses. The added value of public participation in ethics depends on its fit with ethical requirements. If it is implemented in institutionalized contexts, public participation acquires the value of adding legitimacy to expert-led configurations. A lack of time and resources to properly design, implement, and monitor participatory processes can also create a disconnect with the fundamental principles adopted by the organizing institutions. The involvement of human participants in any R&I process demands high ethical standards that go beyond standard procedures. The dividing line is therefore between a participatory process and an *ethical* participatory process.

From conception to *ex post* evaluation, participatory practices need to be subject to *ethical reflection* that highlights the issues, values, and norms in tension in the context under consideration, taking into account the pluralism of values and moral theories, but also the objectives pursued: which target groups should be engaged and how? From the perspective of responsibility in R&I—and considering the different normative meanings of responsibility (Doorn, 2012; Pellé & Reber, 2016; Reber, 2019; Van de Poel & Sand, 2018)—ethics goes far beyond compliance procedures, tending towards an ethical analysis, as a space for deliberation that allows for discussions about values in society, based on different perceptions of right and wrong (Brom et al., 2015). This ethical analysis focuses on ethical practices (compliance with ethical norms) and

guides reflection on dilemmas when moral principles conflict with one another. It is accompanied by an evaluation based on ethical principles (values, norms), which include individual rights, benefit-harm principles, justice principles, and virtues (Shelley-Egan et al., 2015). Participatory methods in R&I are both a democratic approach and a means of enriching the assessment and decision-making related to the specific developments under consideration: different conceptions could result in gaps in the distribution of responsibilities due to pluralistic conceptions of responsibility (Doorn, 2012; Pellé & Reber, 2016; Reber, 2019).

3. Participation in Research Ethics Committees

Several types of organizations with a role in ethics review operate at the local, regional, national, and international levels, including RECs, national ethics committees, and research funding organizations (RFOs).[24] In Europe, RECs rarely adopt participatory practices formally, as participatory practices are not particularly common in European regulatory and ethics bodies, except in the case of biomedical research (Giannelos et al., 2022). The rather weak integration of participatory practices stems from a vague definition of public participation and its associated objectives. Given the considerable variability of participatory configurations in terms of their nature (activity, participants, resources), objectives, and outcomes, this plurality of configurations blurs the definition and the link to ethical grounds. RECs are confronted with participatory practices

[24] This list extends to REC associations and networks; government organizations and councils; universities and research institutes; associations of universities and research institutes; academies of science and associations of academies of science; academic and professional R&I organizations; companies and trade and industry associations; civil society organizations; standards, certification, and accreditation organizations; university ethics centres; and departments and individuals (see Shelley-Egan et al., 2015).

mainly in the context of reviewing research proposals involving human participants, in relation to the main principles of bioethics: autonomy, beneficence, non-maleficence, and justice. These principles can be found in both non-legally binding and legally binding instruments. They are based on the fundamental principle of the primacy of the human being over all other interests. In cases where participants are involved in the work of the RECs, these ethical principles are valid but not sufficient to ensure ethical participation. These cases do not cover the full range of participants who may be involved but are representative of the specific types of audiences that European regulatory bodies[25] typically deal with. Outside the health sector, general categories are used: this is characteristic of general participatory mechanisms that do not necessarily have a deeper connection to ethical grounds. In other words, participatory approaches are underdeveloped in their institutionalized formalization.

Two possibilities follow from this observation: either regulators do not particularly need public participation mechanisms, or regulators do not have an overall framework that would facilitate a broader or more sophisticated approach to participation. In the first case, the lack of participation mechanisms could limit their activities to expert-driven processes. In the second case, the lack of a stabilized framework is not a problem specific to regulators, as it may also affect RECs as direct beneficiaries. However, the French experiment with the *États généraux de la bioéthique* (bioethics convention) (Reber, 2010) took place three times in three different ways (publicized, confined, disseminated), although it was forgotten in the announcement of a possible (national) Citizens' Convention on end-of-life issues,[26] which are easier to manage than bioethics in general. However, the link between ethics and participation is not a field

[25] RECs, research integrity bodies, ethics councils and ethics advisory bodies, professional organizations or NGOs, and EU institutions.

[26] See https://www.lecese.fr/actualites/convention-citoyenne-cese-sur-la-fin-de-vie-premiere-reunion-du-comite-de-gouvernance

of reflection for philosophers: the fields to which this approach is applied are those that tend to be overtaken by reality. These observations mean that the philosophical method needs to be improved and evaluated.

In the context of RECs' work, participation can be considered either at the level of the research project under review or at the REC's initiative. The added value of an *ethics framework* could be seen at all stages of R&I processes, complementing the RECs' current functions and activities. In all cases, an *ethics framework* for participation would provide benchmarks for establishing feedback mechanisms and increasing the responsibility and accountability of the research and innovation process to the participants involved.

4. Proposal for a General *Ethics Framework*

An empirical study carried out as part of the European PRO-Ethics project[27] explored the contours of ethics in the case of participatory practices—involving citizens and stakeholders in R&I processes—and identified gaps in the treatment of ethics and moral values.[28] A survey of European RFOs[29] examined the ethical underpinnings that these agencies strive for in their activities, in order to determine the basis on which the ethical dimension of participatory practices is constructed in each case,

[27] The PRO-Ethics project (*Participatory Real Life Experiments in Research and Innovation Funding Organisations on Ethics*) is a European project (Horizon 2020) involving a consortium of 15 partner institutions (including academic institutions, international organizations, and RFOs). The project, which runs from 2020 to 2024, is attempting to define the path towards ethical participation in research and innovation processes in Europe.

[28] For a more in-depth approach to these issues, see Giannelos et al. (2022).

[29] The sample studied was limited to 10 RFOs across Europe, which were investigated using two surveys and contextualizing interviews about their practices.

taking into account the different normative meanings of responsibility. It is surprising to find that understandings and approaches to what ethics is are very different. This is also true for participatory experiences: general conceptions of what ethics is vary (Reber, 2011). Furthermore, the RFOs showed a tendency towards operationalization and legal compliance in their practices, rather than in-depth ethical reflections on those practices.

In practice, these R&I actors are targeting different ethical foundations. It has been observed that these RFOs understand ethics according to different conceptions: moral problems, moral values, moral theories, or conceptions that are closer to legal compliance than to ethical reflection—including the European framework for RRI and national or European regulatory frameworks. Because these actors are drawing on different ethical foundations, they apply different understandings of ethics in their activities, rather than a homogeneous approach. This empirical study showed that the main ethical motives cited by RFOs are, first, compliance with national laws; second, compliance with European laws; and third, compliance with moral values. These results undoubtedly indicate that, among the ethical motives cited by RFOs, compliance with the law currently takes precedence over ethical concerns.

To continue this research[30] on how to define ethical participation in the context of R&I, and in light of these findings, an *ethics framework* for participatory practices has been designed. Although the target audience of this *ethics framework* is mainly European RFOs, it can also be extended to any institution concerned with participatory practices or ethics in R&I. The limited understanding of ethics and public participation mechanisms is the reason for this *ethics framework*. This observation is guided by the initial intuition that there are advantages in linking ethics and participation. Moreover, given the heterogeneity of the "citizens" and "stakeholders" categories, more specific categories of participants and

[30] This research was carried out by the authors of this paper within the framework of the European PRO-Ethics project.

specific categories of participatory activities would allow a better analysis of who participates, when, working towards what outcomes, and with what kind of moral justification.

From this perspective, the purpose of such an *ethics framework* is twofold: it would first offer common classifications, providing the possibility of shared benchmarks in terms of participatory activities and participants, as well as in terms of the ethical concerns to be taken into account. Second, such an *ethics framework* would provide a set of guidelines, to guide the design, implementation, and evaluation of ethical participatory practices. Such an *ethics framework* would finally respond to the difficulty of defining what ethical participation is, on the one hand, and of benefiting from a useful ethics framework, on the other, both at the operational level (design, implementation) and at the evaluation level (assessment and justification of the added value of public participation initiatives).

5. The Ethics of Participation: Testing a Flexible, Pluralist Theoretical Framework

The conditions for the design, implementation, and monitoring of ethical participatory practices (in the sense of an ethical way of introducing new publics into R&I processes) require us to move beyond the issue of legal compliance. In the context of institutionalized public participation, the meaning of accountability and integrity come up against the need for a case-by-case approach and the need to consider the whole chronology of the participatory process. This would imply incorporating the dimensions of anticipation, reflection, and inclusion into policy and decision-making with a variety of audiences and stakeholders. Matching the types of participants, the type of participatory activity, and the overall configuration in terms of resource allocation and expectations is also essential to achieve ethical participation. An ethical approach implies moving

beyond its legalistic form (found in *soft law* and ethical compliance systems) towards a reflexive form of accountability.

Several difficulties can be expected in the implementation of an ethical participatory process. First, given ethical pluralism, there are several paths that can be taken beyond the standard, ethically under-determined ethical procedures. As a flexible reflection on processes, options and choices, ethical expertise ensures that responsibility governs the R&I processes under consideration. Furthermore, a thorough ethical analysis requires the identification of ethical aspects (e.g., moral dilemmas, ethical issues) related to a specific project or topic as well as the recognition of conflicting ethical issues, if any. Finally, financial and human resources can be a barrier. Other barriers have been identified, such as R&I institutions' capacity to engage in ethical participation. These obstacles, which also affect RECs, are linked to unequal conditions: unequal structural resources (human or financial), poor valuation of ethical expertise, and organizational constraints that limit the capacity to pursue a participatory initiative over time. Overall, the main conditions for success are the ability to follow through with all stages of the participatory process, from launch to *ex post* evaluation, the ability to provide appropriate resources, and the ability to identify the limits of knowledge and seek external expertise. In addition, RFOs' unequal understanding and capacity to consider the added value of ethics to R&I is another difficulty (Giannelos et al., 2022). This calls for the development of responsive mechanisms that push the boundaries of existing ethical review procedures beyond their standard form, in line with the responsible innovation perspective.

An *ethics framework* allows for flexibility and contextual translation of suggested actions on a case-by-case basis: as a flexible construction, this framework assumes that, without contextual adaptation, a universal recipe for ethical participation would be counterproductive. In this respect, the *ethics framework* provides stable definitions and categories for key participatory features (types of activities and participants); as a

whole, it functions as both a roadmap and a checklist. Therefore, RFOs, RECs, or any other regulatory body or R&I institution considering assessing, proposing, or introducing public participation mechanisms in their own activities can refer to this guidance, regardless of the context. Thus, the categories introduced in the proposed *ethics framework* can be applied flexibly, according to different groupings. For example, participants can be categorized according to their degree of involvement in the R&I process, distinguishing between relevant target groups (e.g., patients or young people), end users and consumers, and finally laypersons —including so-called *citizen science*.

6. Conclusion

The added value of public participation for ethics depends on its fit with ethical needs. There is a real danger in seeing it as a miracle solution, since participatory practices have become a trend—participatory or deliberative—without necessarily having the means to link them to ethics. Certainly, ethical evaluations can benefit from participatory practices, simply because they diversify the formalized processes and sometimes disrupt the usual viewpoints by introducing an empirical collection of critical factors. Above all, this is an opportunity to better understand the modes of questioning themselves and to imagine new responses to accompany this research when compromises are found. In the context of responsible innovation, the participation of citizens and stakeholders can have an important leverage effect on scientific and technological developments. To achieve this, however, guidelines are needed. The guidelines we have identified here point to the need for a flexible ethics framework, with an adaptive orientation, to ensure that ethics and participation can optimally merge and produce two outcomes: more ethical participation that respects participants and participation that enriches ethical reflection.

So far, RECs have favoured a limited approach to citizen participation, although an important precedent is the case of biomedical research, where participant involvement is framed by regulations (both binding and non-binding). However, ethical participation is not limited to the application of existing ethical principles, and institutionalized participatory processes would benefit from a general common orientation. To ensure ethical participation, the common adoption of stable meanings and tools to effectively assess the right conditions and added value throughout the life cycle would ensure that participation is only used when the right conditions are met. Citizens' and stakeholders' participation in R&I can be a lever for ethics, provided that the participation itself is ethical. This meeting of the two worlds of participation and ethics has already taken place, for example in France with the three *États généraux de la bioéthique* (Reber, 2010). However, these were highly improvisational. Let us hope that the Citizens' Convention on assisted dying, which recently took place in France, will prove to be less so. It is unlikely that its steering committee will draw on these reflections, but it is nonetheless true that these questions will guide its analysis and evaluation.

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