

# The arena of academic ethics and research facing the requirements of citizen participation or affected publics: risks, conflicts and conditions.

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**Keywords:** responsible research and innovation; ethics; participatory practices; citizens; research ethics committees.

**Mots-clés:** recherche et innovation responsables; éthique; pratiques participatives; comités d'éthique.

**Abstract:** Ethical reflection can be of use to any actor in the academic and research world, involving different responsibilities: scientific integrity, general or disciplinary – questions relating to ethics committees, research ethics, or even broader responsibilities relating to the uses and possible impacts of the work undertaken. This last type of concern has been taken into account under the vague notion of responsible research and innovation (RRI), which includes ethics at all levels, and therefore scientific integrity, but also participation and open science. However, it is not easy to combine ethics, participation and openness. This perspective thus proposes a renewal of the reflection on the categories of responsibility and integrity in Research and Innovation (R&I), as well as on the conditions of the possibility of ethical participation, in regard to the publics involved, the operating modes and the purposes targeted and included in its operationalization.

**Résumé:** La réflexion éthique s'applique à tout acteur du monde académique et de la recherche, sollicitant différentes responsabilités: intégrité scientifique, générale ou disciplinaire ; questions relevant des comités d'éthique ; éthique de la recherche ou dans le cas de projets financés ; voire responsabilités plus larges visant les usages et les impacts possibles de leurs travaux. Ce dernier type de préoccupation a été pris en compte sous la notion vague de recherche et d'innovation responsables (RRI), qui inclut l'éthique à tous ses niveaux, et donc l'intégrité scientifique, mais également la participation et la science ouverte. Mais conjuguer éthique et participation de publics hétérogènes ne va pas de soi. Cette perspective propose donc un renouvellement de la réflexion sur les catégories de responsabilité et d'intégrité dans la Recherche et l'Innovation (R&I), ainsi que sur les conditions de possibilité d'une participation éthique, en regard des publics impliqués, des modes opératoires et des finalités visées et incluses dans son opérationnalisation..

## Introduction

In science and technology developments, participatory initiatives introduce new publics that can be beneficial to research projects or evaluation processes, if combined with an enhanced consideration of ethical issues, beyond the mere assessment of ethical compliance. At the same time, ethics can open up new avenues for public participation. Across the variety of configurations of public participation in Research and Innovation (R&I), the adequacy of the process, its legitimacy and compliance with notions of responsibility, integrity and accountability are usually difficult to achieve without proper guidance. The contribution of an ethical participatory activity in Research and Innovation (R&I) can enhance the overall quality and legitimacy of the R&I process. Adequate and qualitative participatory processes are not easy to establish despite several attempts and existing frameworks regarding public participation (Fiorino 1990; Davidson 1998; Rowe and Frewer 2000; Rowe and Frewer 2005; Slocum 2003; Blok, Hoffmans and Wubben 2015). Reversely, ethics is confronted with conceptual difficulties and uneven resources to be handled in a way that can ensure responsible innovation.

Combining ethics with participation in R&I results in a two-way virtuous circuit. This paper will focus on R&I ethics and participatory practices from the viewpoint of institutions conducting R&I, so as to clarify the connection of participation with ethical principles, and to investigate the conditions under which research ethics committees (RECs) could benefit from ethical participatory practices. This presentation is built upon two assumptions: the first one is that participatory practices might bring an added value to the existing functioning of RECs. The second assumption is that the degree to which these participatory practices connect with ethics is varying, hence their added value too.

The main hypothesis is that an ethics framework for participatory practices might be of use for European regulatory bodies dealing with ethics, both for the evaluation of R&I processes involving participants, or in agency's processes involving participants, considering that ethical guidance should intervene early on in R&I processes (Van den Hoven 2014). An ethics framework would provide guidance in the design, implementation and assessment of participatory practices whenever these might be useful. Public participation can be beneficial to ethics; however, this might be dependent on the extent to which an “ethical” participation can take place.

## The “quick fix” of public participation facing responsibility and integrity

From the perspective of responsible research and innovation (RRI) and responsible innovation

<sup>1</sup>, the concept of responsibility calls into question the future orientation we aim at as a society (Owen and Pansera, 2019) and offers a more responsive approach to societal grand challenges (Von Schomberg 2013; European Commission 2014), through a broader understanding of responsibility towards society or stakeholders (Van de Poel and Sand 2018). Responsible innovation stems as a way to tackle radical uncertainty (Grinbaum and Groves 2013), while public dialogue – or deliberation – could be considered as a genre for uncertain futures (Reber 2016). In line with responsible innovation, R&I processes are bound to adhere to principles of sustainability, social desirability, and ethical acceptance (Von Schomberg 2013), while responsibility is distributed within a network of actors (Doorn 2012; Stilgoe 2013). With an approach rooted in responsible innovation, notions of democratic governance, responsiveness and responsibility are key concepts inviting for ethical and inclusive deliberation processes, embracing broader perspectives in terms of publics and stakeholders (Owen, Macnaghten and Stilgoe, 2012).

Developing R&I in a responsible way implies to address research, science and technology developments through public dialogue, serving four main objectives: to gain public acceptance, to inform governance about future societal consequences of R&I developments, to make governance of science and technology more accountable, to gain public understanding to avoid tensions (Sykes and Macnaghten 2013). Having innovation processes that are more responsive to social needs and values and anticipate the uses and societal consequences (Van de Poel and Sand 2018) still has some gray areas. Although public engagement goes back to the 1970s with technology assessment, five decades later and after a variety of participatory forms, still essential questions remain unresolved as to why, how and in view of what quality such processes are undertaken (Pellé and Reber, 2016).

Considered from the angle of responsibility in R&I – and in view of the different normative meanings of responsibility (Pellé and Reber 2015; Van de Poel and Sand, 2018) –, ethics expands far beyond compliance procedures, towards an ethical analysis, as a deliberation space allowing for discussions on values in society, based on perceptions on right and wrong (Brom et al. 2015). This ethical analysis covers ethical questions (conformity with ethical standards), ethical issues and ethical dilemmas in the event of conflicting moral principles – with an assessment

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<sup>1</sup> RRI is a policy discourse that has been initiated by the European Commission (Science and Society program), whereas RI has emerged from academic roots.

based on ethical principles (values, norms) that cover individual rights, principles on benefits and harms, fairness principles and virtues (Shelley-Egan et al. 2015). Participatory methods in R&I are both a democratic approach and a means to enrich the assessment and decision making related to the specific developments considered: different conceptions could entail gaps in the distribution of responsibilities due to the pluralism of the conceptions of responsibility (Doorn 2012; Pellé and Reber 2016; Reber 2019).

The added value of public participation to ethics is conditioned by its adequacy with ethical requisites. The risk of a “quick fix” arises as participatory practices have become a trend – a participatory or deliberative one –, without the means to connect it to ethics. On the other hand, ethics assessments can benefit from participatory practices to the extent that these latter diversify formalized processes and disrupt the usual views by introducing an empirical collection of critical factors. Quite often, public participation is either non-existent or implemented in institutionalized contexts as an add-on that brings some legitimacy to expert-led configurations. The lack of time and resources to properly design, implement and monitor participatory processes brings a disconnect with the core principles embraced by the organizing institutions. The involvement of human participants in any R&I process raises the bar with respect to ethics, beyond the point of standardized procedures. The dividing line stands between a participatory process and an ethical participatory process. Defining an ethical participation is the assumption guiding this paper – following the findings of the PRO-Ethics project –, through the attempt of bringing together ethical principles with participatory features.

In the context of institutionalized public participation, the meaning of notions of responsibility and integrity is confronted with the need for a case-by-case approach and the need to consider the whole timeline of the participatory process. Responsiveness entails to include dimensions of anticipation, reflection and inclusive deliberation to policy and decision-making (Owen et al. 2012) with a diverse set of publics and stakeholders. The matching between the types of participants, the type of participatory activity and the overall configuration in terms of resources allocation and expectations is also key to having an ethical participation. In line with responsible research and innovation principles, ethics extend their legalized form (to be found in soft law and ethical compliance schemes) towards a reflexive form of responsibility. Considering ethical pluralism, several paths can be followed, thus reducing the adequacy of standard ethics procedures. An in-depth ethical analysis requires the identification of ethical aspects (e.g. moral dilemmas, ethical questions) related to a specific project or topic considered, as well as the recognition of conflicting ethical issues, if this occurs. As a flexible reflection, on the process, the options and choices, ethical expertise ensures responsibility is governing the R&I processes considered.

Several types of organizations with a role in ethics assessment operate at local, regional, national and international level, among which: RECs, national ethics committees and research funding organizations (RFOs)<sup>2</sup>. These latter have been the focus of the PRO-Ethics project, which has developed an Ethics Framework for participatory practices in R&I. As it has already been acknowledged by Shelley-Egan et al. (2015), RFOs have a different understanding and focus on ethics assessment, which might be carried out internally or externally. By recognizing and embracing the pluralistic interpretations of responsibility, R&I actors are more likely to make appropriate choices (Reber 2019). However, we have demonstrated (Giannelos, Reber and Doorn 2022) the uneven understanding and capacity of RFOs when it comes to considering the added value of ethics to R&I. We have also steered the ethics of R&I into the direction of responsive mechanisms that push the boundaries of the existing ethics assessment procedures in their standard form, in line with the perspective of responsible innovation.

Within the scope of the work of RECs, participation can either be considered at the level of the research project under evaluation, or under the REC's initiative. We could call the first form an “embedded participation”, being part of the R&I project under assessment. For participatory forms initiated by the REC, two cases could be considered: either a participatory process that the REC suggests to the leaders of the research project, and that could be labelled “suggested participation”, and what we could call a “reflexive participation” if the REC considers the benefits of an external expertise within its own organization. In the three cases, public participation bears a variety of forms and connections to ethics, and the extent to which a participatory process can be considered as ethical is more than a matter of compliance to the basic principles encompassed in the involvement of human participants in (biomedical) research. Ethics and participation reveal a dynamic correlation, where ethics and participation show reciprocal benefits. In this respect, the added value of an Ethics Framework could be perceived at all stages of R&I processes and be complementary to the existing role of RECs, as shown in the following table:

| <b>Research &amp; Innovation phase</b> | <b>Before R&amp;I starts</b> | <b>During R&amp;I</b> | <b>After R&amp;I is completed</b> |
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<sup>2</sup> This list expands to: Associations and Networks of Research Ethics Committees, Governmental Organizations and Councils, Universities and Research Institutes, Associations of Universities and Research Institutes, Science Academies and Associations of Science Academies, Academic and Professional Organizations in R&I, Companies, Business and Industry Associations, Civil Society Organizations, Standards Organizations, Certification and Accreditation Organizations, Academic Ethics Centers and Departments, and Individuals. See Shelley-Egan et al. 2015.

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|--|--|--|---|
| <p><b>Role of RECs<sup>3</sup></b></p>           | <ul style="list-style-type: none"> <li>● Providing information to researchers</li> <li>● Ethics review of the research proposal</li> </ul>   | <ul style="list-style-type: none"> <li>● Second review if needed</li> <li>● Follow-up of the project, in its ethical dimensions</li> </ul> | <ul style="list-style-type: none"> <li>● Review of the reports</li> </ul> |
| <p><b>Added value of an Ethics Framework</b></p> | <ul style="list-style-type: none"> <li>→ Option A (<i>embedded participation</i>)<sup>4</sup> If a participatory process is already embedded in the project proposal, the Framework will help assess if the right dispositions have been taken for an ethical design.</li> <li>→ Option B (<i>suggested participation</i>) If there is no participatory process, the Framework will help assess if a participatory process could be of benefit and, if so, provide guidance at each stage of the project (inception; during; or for the ex-post assessment of the project).</li> <li>→ Option C (<i>reflexive participation</i>) If the project does not require any participatory process but that the review/assessment of the project could benefit from external participants to the composition of the REC (e.g. external experts/scientists), then external expertise could be considered as a participatory activity. In this case, the Framework could be applied (in terms of external participants, at agency level).</li> </ul> |  |   |

In all cases, an Ethics Framework would provide comprehensive guidance, thus allowing for feedback mechanisms and a greater responsibility and accountability of the R&I process towards the involved participants. It would also encourage participation whenever relevant and, on the contrary, suggest abandoning participation that cannot meet the basic ethical guidelines suggested, either because of a lack of knowledge or means to design and implement it adequately.

## Public participation in institutionalized mechanisms

Public participation processes have become an ever-expanding field, confronting expert-led governance to its shortcomings, by correcting democratic deficits in policymaking (Fung 2008), strengthening the fabric of democracy (Fagotto and Fung 2014), effectively addressing moral disagreement in politics (Gutman and Thompson 2004) and empowering wider social agency (Stirling 2005). In Europe, research ethics committees (RECs) do not necessarily embrace participatory

<sup>3</sup> Council of Europe (2012). *Guide for Research Ethics Committee Members*.

<sup>4</sup> We introduce this terminology (this typology the two others) to differentiate the level of intervention of public participation.

practices in a formalized way. A study led in the course of the PRO-Ethics project<sup>5</sup> explored the contours of ethics in the case of participatory practices – covering citizens and stakeholders' participation in R&I processes. This study has revealed that participatory practices are not particularly prominent in European regulatory bodies and ethics bodies, except in the case of biomedical research. The rather weak integration of participatory practices seems to depend on a vague definition of public participation and of the purposes associated with it. As participatory configurations (activity; participants; objectives; resources) considerably vary in their nature, objectives and outcomes, this plurality of configurations blurs the definition and the connection to ethical grounds.

RECs are confronted with participatory practices mainly in the case of research proposals reviews involving human participants. These cases do not cover the whole extent of participants that might be involved but are representative of the specific types of public that European regulatory institution<sup>6</sup> usually deal with. Beyond this sectoral prominence (i.e. health sector), broad categories are used, which is symptomatic of general participatory mechanisms that are not necessarily making a deeper connection to ethical grounds. In other terms, participatory approaches are under-developed in their formalized/institutionalized application. To guarantee an ethically sound process, regulatory bodies might use participation in their activities, but the connection of participation with ethics is still under-explored.

Two hypotheses derive from this observation: either that regulatory bodies are not particularly in need of public participation mechanisms; or that regulatory bodies do not benefit from a comprehensive framework that would facilitate a more acute or fine-tuned approach to participation. In the first case, the lack of participatory mechanisms might confine their activities in expert-led processes, which for some cases might stumble across issues of public acceptance, or from the feedback of affected publics – those concerned in the first place from the R&I developments at stake, which also grants the democratic quality of the activities in question. In the second case, the absence of a stabilized framework is a non-specific issue for regulatory bodies, but it might also concern RECs as direct beneficiaries. In other terms, if a comprehensive ethics framework for participatory practices in R&I would allow for a more acute methodological approach, a better

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<sup>5</sup> Participatory Real-Life Experiments in Research and Innovation Funding Organisations on Ethics (PRO-Ethics): a European Horizon 2020 project, gathering a consortium of fifteen partner institutions (academic institutions, international organizations and research funding organizations), trying to define the pathway towards an ethical participation in R&I processes.

<sup>6</sup> RECs, research integrity bodies, ethics councils and ethics advisory bodies, professional organizations or NGOs, and the European Union's institutions.



identification of ethical tensions, and the legitimacy of participation, this would be beneficial also to regulatory bodies.

Within the spectrum of RECs' activities, the main relevant documents mentioning participation are the EU regulation on clinical trials on medicinal products for human use<sup>7</sup> and the Guide for Research Ethics Committee members<sup>8</sup>. The first document mentions the involvement of “at least one layperson” in the process of applications' assessment: the participation of the general public is here indicated as beneficial in decision-making processes for clinical trials. The second document mentions the constant involvement of diversified publics as part of the recruitment of REC members, so as to ensure a diversity of profiles, and thereby a diversity of views.

In the work of European regulatory institutions specialized in the field of R&I, participation is mostly represented in the field of biomedical research and covers the involvement of human beings in the review of research proposals, with a view to the main ethical principles in bioethics: autonomy, beneficence and non-maleficence, and justice. These principles, to be found in non-legally binding instruments as well as in legally binding instruments, fall under the core principle of the primacy of the human being, over any other interests. Considering the case when participants are brought in the work of RECs, these ethical principles are valid but not sufficient to guarantee an ethical participation.

In the case of ethics advisory bodies, the publication of the European Group on Ethics in Science and New Technologies (EGE) on “The Ethical implications of new health technologies and citizen participation”<sup>9</sup> offers a categorization of participation actors “stakeholders, lay persons, patients and consumers [...], organized interest groups, lobbies and corporate bodies” as potential participants, while citizen science is considered as an “active” participatory form. These categories offer a greater diversity than the usual categories found, limited to patients and research participants. Considering the field of research integrity, with institutions such as ENRIO or the European Network for Academic Integrity (ENAI), participation is not a dimension currently developed. However, research integrity bodies and representative institutions of this field are relying on a strong

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<sup>7</sup> European Parliament and European Council (2014, 16 April). Regulation (EU), N° 536/2014 on clinical trials on medicinal products for human use, and repealing Directive 2001/20/EC. *Official Journal of the European Union*, L 158, 27.5.2014, pp. 1–76. Retrieved from:

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<sup>8</sup> Council of Europe (2012, April). *Guide for Research Ethics Committee Members*. Steering Committee on Bioethics. Strasbourg: Council of Europe. Retrieved from:

<https://www.coe.int/en/web/bioethics/guide-for-research-ethics-committees-members>

<sup>9</sup> European Group on Ethics in Science and New Technologies (EGE) – European Commission (2015). *The ethical implications of new health technologies and citizen participation*. Luxembourg: Publications Office of the European Union.



basis of ethical principles (e.g. transparency, privacy, sustainability) which form the basis of public participation. Across all these institutions, participation bears a connection with the ethics of R&I, however, the granularity of the participatory approach seems to be context-dependent, with targeted publics in the health sectors (patients) while other sectors (as big data) usually target the general public.

The risk of unfit processes is that the initial expectations are not in adequacy with the resources and the configuration of the participatory initiative, thus leading to a poor informative output or the under-exploitation of the outputs. In the field of biomedical research, participatory mechanisms are mainly represented in the involvement of participants (usually patients or research participants): the ethical checklists offer a comprehensive coverage of main ethical issues, which is not the case in other R&I fields. Beyond biomedical research, participants are not necessarily involved as direct targets of the research (research participants, i.e. research in human beings, in biomedical research) but can be diverse categories of the public, intervening either as citizens/lay people, or end-users, or scientists etc., bringing an exterior viewpoint to the R&I process.

## **Conclusion**

Addressing moral considerations properly guarantees an ethical design of R&I as well as good economic outcomes (Van den Hoven 2013). In line with responsible innovation, the participation of citizens and stakeholders can have an important leverage on science and technology developments: however, to achieve this, guidelines are needed. This paper has introduced such guidelines, to ensure ethics and participation can adequately be merged. The expansion of participatory practices poses the question of their institutionalization and their framing from the perspective of R&I governance. So far, RECs have a limited approach to participation, however with a strong precedence in the case of biomedical research, where the involvement of participants is framed by strong binding and non-binding regulations. The main learning is that ethical participation is not limited to the application of the existing ethical principles and that institutionalized participatory processes could benefit from a common guidance.

To ensure an ethical participation, a common adoption of stable meanings and tools to effectively assess the proper conditions and the added value throughout the whole timeline would ensure participation is only used whenever the right conditions are met. A stabilization of meanings and practices through common guidelines would avoid the uneven understanding of the mechanisms engaging citizens or specific affected publics. Having a more responsive governance of science and technology points to the adoption of ethical participatory practices: in this perspective, an Ethics Framework would be beneficial.

Ethics offers a resourceful leverage for participatory practices, ensuring their added value and legitimacy, both towards the participants themselves and in terms of social impact. Connected to participation, ethics are enhanced to a level that exceeds the usual activities of R&I assessment undertaken by RECs and regulatory bodies. In turn, when connected to ethics, participatory activities can level up the ethics of R&I by the numerous benefits outlined in literature. On that front, the strong assumption of this paper is that without an Ethics Framework, participation cannot effectively endorse ethical principles, since the overlap of actors, activities, timelines and verifications or anticipations requires precise guidance. Its adoption and use by European RECs could arguably allow for a renewed approach to participation through the lenses of ethics. Involving citizens and stakeholders in R&I can be a leverage for ethics, as long as the participation itself is ethical.<sup>10</sup>

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<sup>10</sup> A longer version of this article will be published in: Michelle Bergadaà, Paulo Peixoto (Eds.) *Les nouvelles frontières de l'intégrité*. Caen: EMS éditions [2023].

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