



## Deliverable

D4.3 Results of workshop 1 with ethics committees and research integrity bodies

<b>Project</b>	PRO-Ethics – Participatory real life experiments in research and innovation funding organisations on ethics
<b>Project Acronym</b>	PRO-Ethics
<b>Project Number</b>	872441
<b>Deliverable:</b>	D4.3
<b>Submission Date:</b>	30.10.2020
<b>Responsible Author(s)</b>	Madeleine Gabriel, Alex Glennie, Juliet Ollard

**Disclaimer:** The present Paper Manuscript on Participatory Practices and Ethics Issues in Innovation has been submitted to the European Commission for review. The information and views set out in this report are those of the author(s) and do not necessarily reflect the official opinion of the European Union. Neither the European Union institutions and bodies nor any person acting on their behalf may be held responsible for the use which may be made of the information contained therein.



## Document Control Sheet

<b>Work Package Number</b>	WP4
<b>Work Package Title</b>	Stakeholder Dialogue, Reflection and Embedding
<b>Task Number</b>	T4.3
<b>Task Title</b>	Dialogue with ethics committees and research integrity bodies
<b>Deliverable Number</b>	D4.3
<b>Deliverable Title</b>	Results of workshop 1 with ethics committees and research integrity bodies
<b>File name</b>	D4.3_Workshop_1_with_ethics_committees_and_research_integrity_bodies_final
<b>Number of pages</b>	24
<b>Dissemination level</b>	Public
<b>Main author</b>	Madeleine Gabriel, Alex Glennie, Juliet Ollard
<b>Quality Assurance</b>	Dorothea Sturn, Stefanie Schuerz (Editing)



## Versioning and Contribution History

Version	Date	Author	Co-Author	Notes
_v01	14.10.20	Madeleine Gabriel	Alex Glennie, Juliet Ollard	First draft
_final	28.10.20	Madeleine Gabriel	Alex Glennie, Juliet Ollard	Finalisation



## Table of Contents

Document Control Sheet	3
Versioning and Contribution History	4
Table of Contents	5
1 Executive Summary	6
2 Introduction	7
3 Context and aims	8
4 Methods	9
4.1 <i>Pre-workshop interviews</i>	9
4.2 <i>Workshop with ethics and integrity experts</i>	9
4.2.1 Workshop goals	9
4.2.2 Preparation	10
4.2.3 Workshop design	10
5 Key findings	12
5.1 <i>To what extent are ethics and integrity bodies concerned with participation?</i>	12
5.2 <i>Defining key terms and vision</i>	12
5.3 <i>Research ethics and participation in RFO-led activities</i>	13
5.4 <i>Research integrity and participation in RFO-led activities</i>	16
5.5 <i>What kinds of engagement work should RFOs be doing?</i>	17
6 Reflections on the task	19
6.1 <i>What went well</i>	19
6.2 <i>What could have been better, and lessons learned</i>	19
7 Conclusions and implications for future engagement activities	20
7.1 <i>Main conclusions</i>	20
7.2 <i>Next steps for T4.3, dialogue with ethics committees and research integrity bodies</i>	21
Annex:	22
1. <i>List of interviewees</i>	22
2. <i>Workshop participants</i>	22
3. <i>Outputs from workshop breakout groups</i>	23



# 1 Executive Summary

Effective stakeholder engagement is essential if PRO-Ethics is to have lasting, sustainable impact. PRO-Ethics needs to draw on the expertise of organisations outside the consortium in order to develop a robust ethics framework and practical, usable guidelines for assessing the ethics of participation processes in innovation processes. Its wider impact also depends on results being taken up and used by organisations beyond the consortium. Work Package 4 is designed to ensure that key stakeholders are meaningfully involved in PRO-Ethics from an early stage and throughout the project.

Task 4.3, dialogue with ethics committees and research integrity (RI) bodies, is designed to facilitate this process. This document describes the results of PRO-Ethics' initial steps to engage this key set of stakeholders. It presents findings from a set of interviews and a workshop conducted between July and September 2020. These activities engaged important stakeholder organisations for PRO-Ethics at both the national and regional levels, including the European Network of Research Integrity Offices (ENRIO), the European Federation of Academies of Sciences and Humanities (ALLEA), and the European Network of Research Ethics Committees (EUREC, a PRO-Ethics partner), as well as academic institutions.

The interviews and the workshop generated a rich set of ideas and questions to be addressed within PRO-Ethics. It highlighted the need for PRO-Ethics to develop a clear set of conceptual definitions for what is meant by 'ethics' and 'participation' in the context of RFOs and the fields of action in which they are running pilot projects. This will enable the consortium to have more specific and solutions-oriented dialogues with research ethics and integrity experts in the next phase of the project, and particularly in relation to the development of the second round of RFO pilots.

Important gaps have also been identified through the activities conducted for this task, highlighting areas where PRO-Ethics can make a novel contribution to the field of citizen participation in research and innovation activities - for example, in relation to developing guidance for ethical practice in informing citizens about participatory processes, ensuring that no immediate harm comes to participants during the process, and developing a common method for modelling risks and benefits for different groups as part of an ethical review process.

These insights will feed into the ongoing work being conducted in WP1 (Ethics of Innovation: Conceptual Framework) and in WP5 (Synthesis – Ethics framework and practical guidelines).



## 2 Introduction

[PRO-Ethics](#) is working with research and innovation funding organisations across Europe to test new, ethical ways to involve citizens in three fields of action: participation in innovation projects, participation in strategy development and participation in evaluation processes. PRO-Ethics will deliver an ethics framework, together with a set of practical guidelines and actionable criteria for assessing the quality and ethics of participation processes.

PRO-Ethics Task 4.3, *Dialogue with ethics committees and research integrity bodies*, aims to gather insights, reflection and feedback from research ethics and research integrity bodies. The overall goal of this task is to build a community of ethics and research integrity bodies that are engaged in the progress and outputs of PRO-Ethics. These bodies potentially have a dual relationship with the project. On the one hand, they may be willing to contribute their expertise to the development of the pilots and ethical framework. On the other, the project may provide useful learning and case studies to develop their own practices and resources to support the institutions they serve.

Task 4.3 runs from month 6 of the PRO-Ethics project (June 2020) to month 38 (February 2023). Over this time, PRO-Ethics partners delivering this task (Nesta, EUREC and EUREKA) will carry out a total of 25 interviews with representatives from research ethics and integrity bodies, and deliver two interactive workshops.

This deliverable report focuses on the first phase of this work. Between July and August 2020, PRO-Ethics partners carried out the first tranche of interviews with eight research ethics and integrity experts (the remaining 17 interviews planned as part of this task will be conducted in two further tranches over the duration of the project). These interviews supported preparation of the first workshop with ethics and integrity bodies, which was run in September 2020. Although initially intended to take place in Brussels, the workshop was switched to an online format because of COVID-19 restrictions.



### 3 Context and aims

The fields of research ethics and integrity are concerned with the principles and practices that ensure the ethical and responsible conduct of research. The ENERI project, which brings together ethics and integrity experts in an integrated network to share knowledge and enhance the environment for research, provides the following definition<sup>1</sup>:

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

Significant expertise has been developed in these fields around how to govern the participation of humans as research subjects, particularly in the biomedical sciences. Ethics experts may also be familiar with participatory processes in their own work, such as lay involvement on committees. Since PRO-Ethics aims to develop an ethical framework for participation in RFOs' activities, the consortium was keen to seek input from research ethics and integrity experts. Our assumption was that these fields would have significant relevant insight that could inform PRO-Ethics' approach.

Nevertheless, the type of participation that PRO-Ethics is piloting is somewhat different to that which ethics and integrity bodies usually consider. The RFOs in the PRO-Ethics consortium are each delivering 'pilots' that promote the active involvement of civil society actors, end-users, members of the public and other stakeholder groups in RFOs' funded projects, decision-making processes and evaluation activities. These pilots focus on topics ranging from assistive technologies to urban resilience.

This first phase of engagement with research ethics and integrity experts therefore aimed both to draw out how these established fields could **inform** PRO-Ethics' practical pilots (WP2 and 3) and the development of our ethical framework for participation (WP1), and to help identify **gaps and challenges** in ethical principles or frameworks for participation that PRO-Ethics might help to fill over the course of the project.

<sup>1</sup> Braun R., Ravn T. et al. (2019) *RE/RI expert set of indicators for e-database*. ENERI Deliverable 6.2.



## 4 Methods

### 4.1 Pre-workshop interviews

Between July and August 2020, Nesta, EUREC and EUREKA carried out a series of interviews with research ethics and integrity experts. The aims of these were twofold: to introduce the PRO-Ethics project to this group of stakeholders, and to start exploring ethical and integrity issues relevant to PRO-Ethics. These activities sought both to build relationships ahead of the first workshop and to scope relevant issues for discussion at the workshop itself.

PRO-Ethics partners are already well connected in this field. EUREC has members in 23 EU countries as well as relationships with a wide range of institutions focusing on both research ethics and integrity. EUREKA has strong relationships with a network of ethics experts involved in its Ethics Panels. Drawing on these partners' knowledge and institutions identified in PRO-Ethics' earlier stakeholder mapping (Task 4.1), a list of potential interviewees was generated. Although the timing made scheduling somewhat challenging (interviews coincided with the summer break), eight interviews were successfully conducted. A list of participants is included in the appendix to this document.

Interviews were semi structured and carried out via Zoom. Partners devised a standard topic guide to steer the discussions, covering the following questions:

1. To what extent does your organisation deal with the implications of participatory processes? Is it a topic of interest for your organisation and/or your members?
2. What do you see as the main challenges within participatory processes from a research ethics/RI point of view? What do you see as the main opportunities?
3. What ethical/RI issues would you anticipate in PRO-Ethics fields of action - i.e. participation in a) innovation projects, b) strategy, and c) evaluation)?
4. PRO-Ethics aims to create an ethical framework for participation in research and innovation funding activities, and guidance for practitioners in RFOs. How might this add value to the work your organisation does? Is there a gap/need for this type of work? How might we ensure it reaches the right organisations/stakeholders?
5. Are there particular resources you would recommend we look at (e.g. projects, initiatives, committee opinions, papers)? Are there particular organisations or groups within your network whom we should speak to on this topic? Which organisations/networks/countries are leading on these conversations?

### 4.2 Workshop with ethics and integrity experts

#### 4.2.1 Workshop goals

The workshop provided the first formal opportunity for dialogue between PRO-Ethics RFOs and the research ethics and integrity community. When the workshop took place (Month 9 of the project), the [first phase of PRO-Ethics pilots](#) were underway in four of the PRO-Ethics RFOs (WP2). A second phase of pilots was being planned, building on the lessons learned from phase 1 and involving all eight PRO-



Ethics RFOs (WP2 and 3). Meanwhile, work was also underway to develop a first draft of PRO-Ethics' ethical framework (WP1, T1.4).

The workshop was therefore a timely opportunity to invite input from ethics and research integrity bodies. As such, the workshop had three main aims:

1. To start building a community of ethics and research integrity bodies around PRO-Ethics
2. To provide input from ethics and integrity experts on the development of pilots
3. To identify issues that could inform PRO-Ethics' ethical framework

#### 4.2.2 Preparation

Participants were identified through the one-to-one interviews, which provided a chance to explore interviewees' experience and their potential interest in PRO-Ethics. Several of those interviewed were also invited to the workshop. Interviewees were also asked to recommend others who might be appropriate to invite.

Invitees were sent a briefing pack in advance of the workshop giving background information on PRO-Ethics, the purpose of the workshop and the draft agenda. They were also asked to complete consent forms which set out how the workshops would be recorded and how findings would be used and shared.

#### 4.2.3 Workshop design

To complement the individual interviews, the workshop was intended to provide an opportunity for PRO-Ethics partners and external experts to interact and generate ideas collaboratively. Rather than focusing on abstract questions around ethics and participation, it aimed to ground the discussion around real cases - the PRO-Ethics phase 1 pilots - and invite experts to reflect on issues relating to ethics and integrity that could emerge in this type of participatory process. By doing so, the workshop was designed to be useful both for external participants (to get more insight into what PRO-Ethics is doing), RFOs (to have direct feedback on their pilots) and the project as a whole (to draw out more general lessons that could inform future pilots and the development of the ethical framework).

The workshop was structured as follows:

- 1) Welcome, introduction to PRO-Ethics and overview of workshop goals (Madeleine Gabriel, Nesta)
- 2) Provocation: problematising participation in research and innovation decision making (Dirk Lanzerath, EUREC)
- 3) Presentation: Research Council Norway's pilots (Erna Wenche Østrem, RCN)
- 4) Breakout groups: participants were divided into three groups, each with a facilitator from Nesta. Sessions were facilitated using Miro and included:
  - a) Presentation of pilot from RFO speaker
  - b) Facilitated task focusing on two questions:
    - i) What issues relating to research ethics and integrity might arise in this type of participatory process?
    - ii) What approaches (e.g. participation practices, tools and frameworks) can we identify that help address these issues?
- 5) Plenary: Feedback from breakout groups, final reflections and closing remarks (Alex Glennie & Juliet Ollard, Nesta)



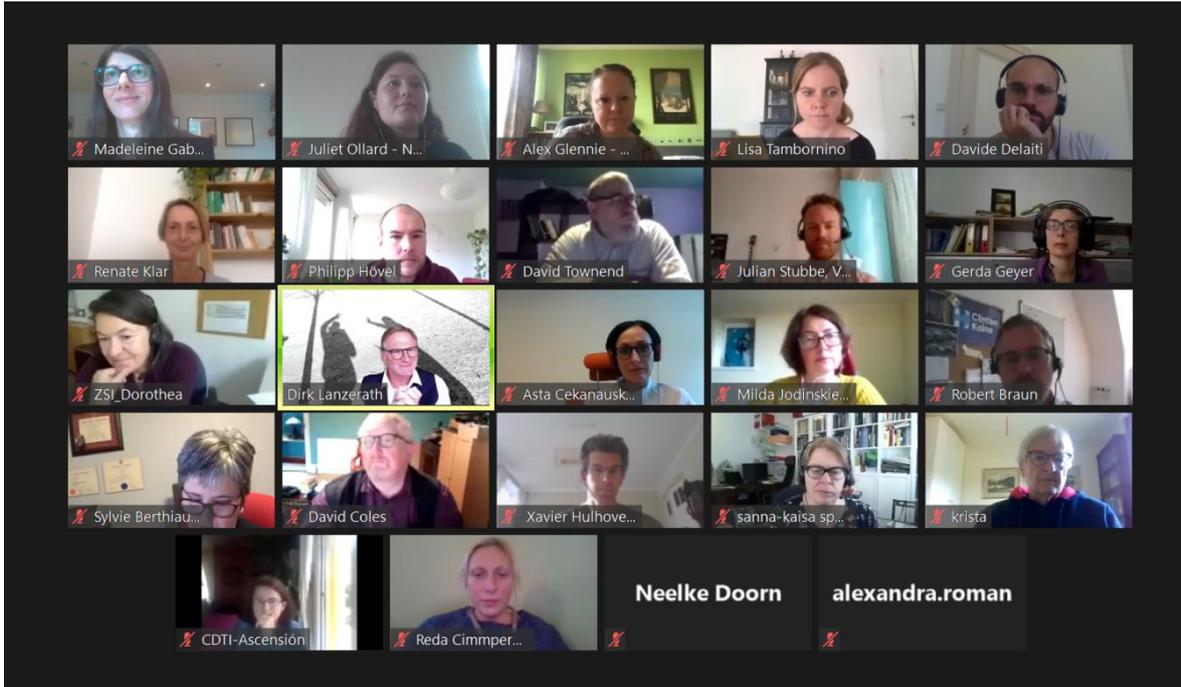


Figure 1: Screenshot from workshop with research ethics and integrity experts, September 2020

## 5 Key findings

This section summarises the results of the interviews and workshop. Results are presented thematically, drawing together key points from across both phases with regard to our overall research questions: how participatory processes currently feature in the work of ethics and integrity bodies; what experts see as the key ethics and integrity issues within PRO-Ethics fields of action; what practices, tools and frameworks currently exist around these issues, and; where there are gaps for the project to fill.

### 5.1 To what extent are ethics and integrity bodies concerned with participation?

Our interviews suggested that participation is a relevant concern both for ethics and integrity bodies, but to a much larger extent in the field of ethics. The involvement of human participants in research is the foundational concern of the research ethics field. Lay representation on ethics committees is a common practice across Europe, and recommended in the Council of Europe’s Guide for Research Ethics Committee Members. In contrast, interviewees noted that research integrity activities themselves remain largely non-participatory, but that the field had engaged with questions about participation with regard to methods such as citizen science (which relies on citizens being trained and capable of carrying out research tasks).

### 5.2 Defining key terms and vision

PRO-Ethics’ theoretical framework (D1.2) states that for the purposes of this project “ethics should not be considered as a toolkit but as a field (from applied ethics until meta-ethics) that extends the regulatory schemes and helps to decipher the legitimacy, the tensions, and the adequacy of processes and legal compliance in regards with contextual criteria”.

Interviews and workshop discussion confirmed the need to define how concepts such as “ethics” and “participation” are operating in PRO-Ethics, and what ideal the project aims for.

Experts pointed out that different rationales for participation could drive quite different practices and focuses for ethical consideration. For example, there is a potential tension between a moral rationale for participation (everyone has an equal right to have input on decisions that affect them) and a knowledge rationale (input from a diverse group will result in better decisions). The former assumes that participants in processes are equal and that it is legitimate for all members of an affected group to participate. It raises questions about how to define this group - for example, whether people have the right to participate on the basis of citizenship or residence of a particular area. The latter meanwhile suggests that participation is legitimate when participants bring something new or different to the process. This in turn raises questions about whose contribution and expertise is valued and who sets the terms as to what contributions are valuable and legitimate. Interviewees pointed out that typically in research processes, the opinions of scientists and others regarded by those in power as ‘experts’ tend to be given more weight than those of lay people.<sup>2</sup>

<sup>2</sup> This issue has been widely discussed in the field of Science and Technology Studies - see for example, Wynne, B (1996) *May the Sheep Safely Graze? A Reflexive View of the Expert-Lay Knowledge Divide*, in Lash et al, *Risk, Environment and Modernity: Towards a New Ecology*. London: Sage.



Related to this is the concept of the relationship between science and society, and the rights and responsibilities of the citizen with regard to research and innovation. Interviewees posed considerations that might help RFOs and similar institutions reach a view on citizens' role in research and innovation. For example, one interviewee gave the following prompts: *"What are the things that the public can decide? What are the points at which citizens need to say "It's beyond me, and I trust others to make decisions on that"?...When should they cede that others have more expertise? How do we help non-expert people to find their limits (as well as thinking about the limits of experts)?"*

### 5.3 Research ethics and participation in RFO-led activities

Interview and workshop discussions highlighted some points of intersection between existing research ethics practice and the demands of participatory processes. The table below presents interviewee and workshop participant suggestions as to how ethical principles could be applied in the context of RFO participatory activities. For the purpose of this analysis we have drawn on the principles set out in the Belmont Report<sup>3</sup>.

<sup>3</sup> National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979). *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research*. Retrieved from <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html>



Table 1: Established ethical principles in research and how they might apply to PRO-Ethics

Principle	Common applications	Considerations in the context of participation	Good practice examples
<p>Respect</p> <ul style="list-style-type: none"> <li>▶ <i>respect for autonomy</i></li> <li>▶ <i>protecting those with diminished autonomy</i></li> <li>▶ <i>ensuring participants enter the research voluntarily and with adequate information</i></li> </ul>	<p>Informed consent (providing information, ensuring comprehension and voluntariness)</p>	<p>Informing participants about the process: the context, existing knowledge, how results will be used. This was mentioned by two interviewees and discussed during the workshop.</p> <p>Presenting information in a way that all can understand (providing for speakers of different languages, avoiding unnecessary use of technical terms)</p>	<p>Four day ideal for deliberative processes, including a phase of learning (OECD Good Practice Principles for Deliberative Processes for Public Decision Making<sup>4</sup>)</p>
<p>Beneficence and non-maleficence</p> <ul style="list-style-type: none"> <li>▶ <i>maximising possible benefits and minimising possible harms</i></li> </ul>	<p>Assessment of risks and benefits</p>	<p>When citizens are involved in taking funding decisions, they may receive pushback from those whose funding proposals are not successful.</p> <p>How are project outcomes/products likely to affect different groups? What technologies might they be used for (can we make judgements about this based on the clients of the company that is being funded, for example)?</p> <p>Cultural sensitivity: is a group being researched for their benefit or just because it's "interesting"? Are the results likely to be desired and used by the group, and to fit within their value system and way of life?</p>	<p>One interviewee suggested that <i>"ethics advisors should ask questions to the companies in order to think about the overall implications of their applications in order to become more aware of these issues and start thinking in advance what they are getting into"</i>.</p>

<sup>4</sup> OECD (2020), *Innovative Citizen Participation and New Democratic Institutions: Catching the Deliberative Wave*, OECD Publishing, Paris, <https://doi.org/10.1787/339306da-en>.



Table 1 (continued): Established ethical principles in research and how they might apply to PRO-Ethics

Principle	Common applications	Considerations in the context of participation	Good practice examples
<p>Justice</p> <p>► <i>achieving a fair distribution of the burdens and benefits of research</i></p>	<p>Selection of research subjects</p>	<p>Designing participatory processes to be inclusive of the needs of different participants and in a way that does not privilege the views or wishes of some groups over others. 3 out of 8 interviewees spoke about this. As one interviewee commented, <i>“the hierarchies that exist in our societies tend to reproduce themselves in research contexts”</i>.</p> <p>Ensuring that your participant pool is actually representative of those who stand to be affected (where this is appropriate/important to the methodology). For example, in the case of the Innoviris pilot, which involves citizens in evaluating proposals for urban resilience projects in Brussels, it’s not simply those who live in Brussels whose lives will be impacted by these decisions.</p>	<p>Remunerating participants</p> <p>Providing childcare</p> <p>Offering support for disabled or vulnerable people</p> <p>Timing activities to fit in with participants’ commitments: <i>“It’s important to choose the time of the day when the process takes place, because this determines who will be able to participate and who won’t. If you set a meeting in the evening, families would have a hard time coming, for example.”</i></p> <p>Ensuring that materials such as questionnaires and surveys are written in inclusive language (e.g. inclusive of different gender identities)</p> <p>Using quotas for recruitment that are representative of demographic characteristics, with up-to-date understanding of different identities: <i>“Gender should be taken into account. E.g. with a quota, you might say 50/50 but gender is more fluid. Female and male 40 and 40, and 20 per cent people who don’t fit in in those two categories...it’s important to make space for everyone.”</i> This can also help mitigate capture of the process by those with particular interests: <i>“If you open something up without any rules, those who will show up are those who are interested and have an agenda, you should instead make sure that you engage all kinds of people”</i>.</p> <p>Demonstrating the importance of the process, and gratitude for citizens’ contribution. Experts suggested measures such as presenting a diploma or certificate, and arranging for a mayor or other figure of standing to make an appearance or send a letter of thanks to participants.</p>



As table 1 shows, the interviews and workshop discussions generated a fair amount of information on how to achieve justice in participatory processes.

However, in the areas of respect and beneficence, as well as the consideration of just outcomes from research in the long term, there was less data. This suggests that PRO-Ethics might be able to fill a gap in terms of guidelines for ethical practice in informing citizens about participatory processes, ensuring that no immediate harm comes to participants during the process, and developing a common method for modelling risks and benefits for different groups as part of an ethical review process.

Participants discussed possible models for an ethical review process at the RFO level both in interviews and at the workshop. For example, how would a common review process be developed for participation, and who should be involved in this? One suggestion was to survey institutions across Europe (and other contexts where there was interest) to find a common value framework. This was also a central theme of the recent workshop on ethical review (T1.3) led by Eureka, which took the ethical review process of its Eurostars programme as a case study. While the shape of an ethical review process at the RFO level is not an issue that PRO-Ethics plans to provide a solution to directly, this is a topic which is relevant for the phase of the project concerned with embedding in national and international systems. For example, this might be a point for discussion with ethics bodies in the final year of the project, and at embedding events within RFO partner countries.

Participants suggested that further discussion should be had on the topic of RFOs forming their own ethics committees. There was a strong steer towards governance models that were anticipatory of ethics issues at an early point in the development of a call, for example via an ethical checklist (an element being explored in some PRO-Ethics pilot I activities).

## 5.4 Research integrity and participation in RFO-led activities

While there was general agreement that research ethics principles are more readily applicable to the PRO-Ethics than those of research integrity, there are aspects of participatory processes that experts identified as relevant from an RI point of view.

The European Code of Conduct for Research Integrity<sup>5</sup> outlines a common framework for self-regulation of research in all scientific and scholarly fields. The Code establishes guiding principles for research, defines good research practices, and specifies what constitutes a violation of research integrity and the proper process for addressing it. The table below uses the framework of the Code to present research integrity issues raised by interviewees and workshop participants.

<sup>5</sup> All European Academies (2017) *European Code of Conduct for Research integrity* (revised edition)



Table 2: Established research integrity principles and application in the context of participation

Principle	Considerations in the context of participation
<p><b>Honesty</b> in developing, undertaking, reviewing, reporting and communicating research in a transparent, fair, full and unbiased way</p>	<p>Designing a transparent process for selecting and using the ideas and recommendations that come from citizen participation (mentioned by 3 interviewees). “A transparent system that shows how you select people’s ideas (you won’t take all of them, and some people might get frustrated if their point of view is not considered so you need to be transparent in order to create trust)”</p> <p>Possibility of tension between participation in research funding decision making and scientific freedom</p> <p>Exercises in topic identification or strategy-setting might be affected by power disparities between advocacy groups</p>
<p><b>Accountability</b> for the research from idea to publication, for its management and organisation, for training, supervision and mentoring, and for its wider impacts</p>	<p>Experts advised that RFOs should be responsible for ensuring that those analysing material resulting from engagement are properly trained to do so (“The material must be analysed by experts, people who have the tools and the expertise to analyse it”), as well as for communicating the process and outcomes effectively with participants, and being able to justify decisions made.</p>
Good research practice	Considerations in the context of participation
<p>Research procedures</p> <ul style="list-style-type: none"> <li>▶ Designing, carrying out, analysing and documenting research in a careful and well considered manner</li> <li>▶ Publishing results and interpretations of research in an open, honest, transparent and accurate manner, and respecting confidentiality of data or findings when legitimately required to do so</li> </ul>	<p>Participatory processes are often contracted out to independent practitioners, and RFOs should ensure that such partners are independent, appropriately skilled and cognizant of their role and responsibilities within a scientific process (e.g. being unbiased). Two interviewees raised this consideration.</p>
Violations of research integrity	Considerations in the context of participation
<p>Plagiarism</p>	<p>Citizen participants might not be aware of the need to keep some information confidential, or know what is appropriate to share publicly and what is not.</p>

## 5.5 What kinds of engagement work should RFOs be doing?

Across several interviews (5 out of 8) there was a feeling that RFOs should use their position in the research and innovation system to carry out participatory discussions on upstream concerns. Interviewees felt that RFOs were well placed to lead dialogue on societal values in the context of R&I, and to carry out education and outreach programmes towards greater scientific literacy and citizenship. Interviewees often pointed to the need for citizen involvement in agenda-setting work,



rather than in projects conceived and designed by RFOs. Workshop discussions continued to raise this theme, together with the warning that this could put RFOs in a position between the two stools of science and politics - a balancing act that must be handled responsibly.



## 6 Reflections on the task

### 6.1 What went well

The key objective for this task was to start building a network for PRO-Ethics with research and integrity bodies across Europe and more widely. This was achieved through a collaboration between Nesta (as WP lead) and the European Network of Research Ethics Committees (EUREC) and EUREKA (as WP partners). EUREC and EUREKA helped to identify a group of highly experienced individuals with an ethics or research integrity background to be interviewed and/or to take part in the first workshop.

The workshop helped to generate a rich set of ideas and questions for PRO-Ethics to engage with. As one workshop participant from a PRO-Ethics RFO reflected, *“several very important aspects were brought up which made me think again that we need a kind of taxonomy for ethics and participation in our project.”* PRO-Ethics now has an initial network of stakeholders whose work and expertise will be valuable in helping to develop the taxonomy that is being put together as part of T1.4, and to shape the development of the second round of pilot projects conducted by RFOs.

### 6.2 What could have been better, and lessons learned

One of the main challenges experienced in some of the interviews and in the workshop was establishing a clear shared understanding of key concepts relating to ‘ethics’ and ‘participation’ in the context of research funding organisations. This definitional work is being carried out by our Work Package 1 partners, but is not yet finalised. This made it difficult to have specific conversations about the particular ethical challenges facing RFOs, and interviewees found it hard to identify which outputs from PRO-Ethics might support their own work. A lesson from this is that it would have been helpful to have involved EUREC and other expert partners more directly in designing the content and the format of the workshop, so as to tailor it more to the needs and expectations of external stakeholders.

The original plan for the first workshop was to hold an in-person event in Brussels, bringing together PRO-Ethics partners with stakeholders from research ethics and integrity bodies for a half or full day session. Travel restrictions due to Covid-19 required the event to be held online, and a decision was taken to make the session two hours long. This proved to be an insufficient length of time to discuss a complex topic with a group of people who did not already have pre-existing relationships. Some participants commented that it would have been better to have a longer session, which would have enabled external experts to spend more time sharing their insights, and more time for whole group discussion. Additional feedback was that it would have been better to spend less time presenting the individual pilots, and more time focusing on generating solutions to some of the problems the RFOs were facing in relation to the ethics of participation.

Despite careful planning in advance and the development of mitigation strategies, some technological challenges were experienced on the day with the two online platforms chosen for the workshop (Zoom and Miro). This meant that not all participants were able to fully engage with the content. A lesson here is to keep the format for future online workshops as simple as possible, and to ensure that one person is solely responsible for the technical facilitation of events.



## 7 Conclusions and implications for future engagement activities

### 7.1 Main conclusions

- ▶ There is a lot of value that PRO-Ethics can draw from existing frameworks, guidance and practices in research ethics and integrity. Experts in these fields could provide useful critical feedback to PRO-Ethics partners as they develop the second round of pilots.
- ▶ There are also some gaps that PRO-Ethics could look to fill. For example, in operational terms, there is a need for ethical guidelines and resources to support RFOs in informing citizens about participatory processes and ensuring that participants are not harmed by their involvement. PRO-Ethics could address this in two ways. First, the consortium could address these topics in the training on ethical participation practices, planned for consortium RFOs as part of Task 2.2. This could draw on and adapt existing good practices from other fields of participation. Where knowledge gaps remain, the Phase 2 pilots could potentially be designed consciously to address them. For example, pilots could develop an 'induction' process for citizens taking part in decision making panels that aims to build their knowledge of ethics and integrity principles, and evaluate this process to see how well it works from the perspective of citizens, RFOs and other participants.
- ▶ More strategically, experts consulted in T4.3 suggested that RFOs and ethics panels would benefit from more guidance on how to model risks and benefits of research and innovation for different groups in society. While ethics reviews consider risks and benefits for research participants, they do not tend to systematically consider the potential impacts of research and innovation on society more widely (the field of Responsible Research and Innovation offers considerable insight on how this can be done). This topic could also potentially be addressed in the training planned for RFOs (T2.2) and in the PRO-Ethics ethical framework and guidelines (WP5).
- ▶ Some existing frameworks and guidance could be updated or adapted to support the participation in RFO activities. For example, the European Code of Conduct for Research Integrity is aimed at researchers, but could be adapted to give guidance to lay participants in RFO activities on issues such as how they should confidential information. Alternatively, the central messages of the European Code of Conduct could be integrated into a new framework for participation.
- ▶ In Task 1.4, PRO-Ethics will establish shared definitions of 'participation' and 'ethics' to be applied in the project. The engagement with research ethics and integrity experts underlined the importance of doing this, and suggested that the project should also be clear about what it sees as the underlying reason for promoting participation - for example, is it a moral imperative, or instrumental (a way to improve research outcomes)?
- ▶ PRO-Ethics consortium and participating RFOs could consider how they will embed ethical practices in activities beyond the pilots. One mechanism could be to set up ethics review panels at an RFO level, where these do not already exist. This would also be useful for funding applicants (such as businesses) that do not otherwise have access to institutional ethics panels.

## 7.2 Next steps for T4.3, dialogue with ethics committees and research integrity bodies

To continue the dialogue with ethics committees and research integrity bodies, Nesta and other WP4 partners will carry out two further tranches of interviews with experts and run one additional workshop.

The initial interviews and workshop suggested that engaging ethics and integrity experts in phase 2 pilot design would be useful. The phase 2 pilot design phase runs from month 16 to 23 (May to November 2021). We propose to carry out the second tranche of interviews with ethics and integrity experts during these months. We will consult with PRO-Ethics partners involved in pilot design to find out what issues they would most like us to discuss with ethics and integrity experts. (PRO-Ethics' project plan also envisages seeking feedback on phase two pilot plans with the project's Advisory Board.)

The initial phase of T4.3 also suggested it is useful to carry out interviews in preparation for workshops. The second and final workshop with research integrity and ethics experts is planned for month 36 (December 2022) when preliminary results of phase 2 pilots are available. This will aim to share findings with a broader range of national and regional ethics and integrity bodies. The third tranche of expert interviews will be carried out in months 33-35 in order to inform the design of this workshop. We will also take on lessons from the first workshop when designing the second, for example, ensuring that sufficient time is given to discussion.



## Annex

### 1. List of interviewees

- ▶ Sylvie Berthiaume, National Research Council of Canada
- ▶ Claudia Chwalisz, Organisation for Economic Cooperation and Development (OECD)
- ▶ David Coles, Newcastle University School of Natural and Environmental Sciences
- ▶ Jeroen van den Hoven, Delft University of Technology
- ▶ Marjo Rauhala, Vienna University of Technology
- ▶ Sanna Kaisa Spoof, European Network of Research Integrity Offices (ENRIO)
- ▶ Tereza Stockelova, Czech Academy of Sciences
- ▶ David Townend, Maastricht University

### 2. Workshop participants

- ▶ Ascensión Barajas, Centre for the Development of Industrial Technology (CDTI)
- ▶ Sylvie Berthiaume, National Research Council of Canada
- ▶ Robert Braun, Institute for Advanced Studies (Vienna)
- ▶ Asta Čekanauskaitė, Lithuanian Bioethics Committee
- ▶ Reda Cimmperman, Research Council of Lithuania
- ▶ David Coles, Newcastle University School of Natural and Environmental Sciences
- ▶ Davide Delaiti, Eureka Network
- ▶ Neelke Doorn, Delft University of Technology
- ▶ Madeleine Gabriel, Nesta
- ▶ Gerda Geyer, Austrian Research Promotion Agency (FFG)
- ▶ Alex Glennie, Nesta
- ▶ Philipp Hövel, European Network of Research Ethics Committees (EUREC)
- ▶ Xavier Hulhoven, Innoviris
- ▶ Renate Klar, European Network of Research Ethics Committees (EUREC)
- ▶ Dirk Lanzerath, European Network of Research Ethics Committees (EUREC)
- ▶ Juliet Ollard, Nesta
- ▶ Erna Wenche Østrem, Research Council of Norway
- ▶ Alexandra Roman, Executive Agency for Financing Higher Education, Research, Development and Innovation (UEFISCDI)
- ▶ Sanna Kaisa Spoof, European Network of Research Integrity Offices (ENRIO)
- ▶ Julian Stubbe, VDI/VDE-IT
- ▶ Dorothea Sturn, Centre for Social Innovation (ZSI)
- ▶ Lisa Tambornino, European Network of Research Ethics Committees (EUREC)
- ▶ David Townend, Maastricht University
- ▶ Krista Varantola, All European Academies (ALLEA) | Council of Finnish Academies



### 3. Outputs from workshop breakout groups

Group 1: FFG

PRESENTATION (5 mins)



PRO-ETHICS CASE 1 FFG: CITIZEN PARTICIPATION IN PROJECTS SUPPORTED BY THE FUNDING PROGRAMME 'RESEARCH4AGE'

The pilot in PRO-ETHICS is an effort to bring on the following issues:  
- The ethical value of the design of end-user involvement  
- The meaning of meaningful patient consent  
- The extent to which ethical approval procedures and approaches are applied throughout the whole development phase and beyond  
- The building of transparency (sharing common language and establish common ground)

PILOT 1 UPDATE

2. a table of activities

Activity	Start	End	Responsible
Introduction and welcome	10:00	10:15	FFG
Overview of the project	10:15	10:30	FFG
Introduction of the pilot	10:30	10:45	FFG
Introduction of the pilot	10:45	11:00	FFG
Introduction of the pilot	11:00	11:15	FFG
Introduction of the pilot	11:15	11:30	FFG
Introduction of the pilot	11:30	11:45	FFG
Introduction of the pilot	11:45	12:00	FFG

PRELIMINARY RESULTS OF THE INTERVIEWS ETHICAL AND INTEGRITY ISSUES RAISED – GENERAL ISSUES

1. Ethical issues were complex, based on the project
2. The extent of participation over phase (ethical process) - what is the problem and needs to be tackled and how to develop the pilot
3. The open part of the pilot (the PRO-ETHICS) is the ethical process, followed by the participant group, the consent process and the ethical approval process (not for participants only, but for the pilot)
4. The consent process is a key element in the ethical process, followed by the participant group
5. The consent process is a key element in the ethical process, followed by the participant group
6. The consent process is a key element in the ethical process, followed by the participant group
7. The consent process is a key element in the ethical process, followed by the participant group
8. The consent process is a key element in the ethical process, followed by the participant group
9. The consent process is a key element in the ethical process, followed by the participant group
10. The consent process is a key element in the ethical process, followed by the participant group

ETHICAL COMMITTEES

1. "Informed" ethics boards or committees often are not suited – focus on medical research or on data protection
2. Ethics boards who have a more participatory / expert role work well
3. Approval of such bodies especially in pilot projects in that research context
4. Consider the role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
5. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
6. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
7. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
8. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
9. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
10. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project

ETHICAL EXPERTISE

1. Knowledge to deal with the ethical issues in the project can be in the consortium, but some need specific external knowledge. Depends on the consortium.
2. "Informed" ethical review often by an ethics board at the national level.
3. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
4. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
5. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
6. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
7. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
8. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
9. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
10. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project

INFORMED CONSENT

1. IC is a key element in the ethical process, followed by the participant group
2. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
3. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
4. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
5. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
6. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
7. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
8. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
9. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
10. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project

COMMUNICATION

1. Target groups should be identified, followed by the participant group
2. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
3. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
4. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
5. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
6. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
7. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
8. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
9. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project
10. The role of the ethics board in the pilot project and how it can be used to the benefit of the pilot project

Q&A (5 mins)

MIRO WARM UP (2 mins)

Create a sticky note and write your name and institution on it - move it so that it sits above the group number/name.

ACTIVITY: IDENTIFYING KEY ETHICAL ISSUES IN THE PILOTS

Based on the presentation of work that has taken place in the first pilot, what are the key ethical issues that RFOs are likely to face in relation to participation in this area of practice (i.e. innovation projects)?

1. Everyone in the group add ideas to the board using post-its (5 mins)
2. Facilitator to cluster post-its and everyone in the group to use green dot votes to select priority issues (5 mins)
3. Facilitated discussion about what can be learned from the experience of research integrity and ethics bodies/experts in relation to key challenges (20 mins)

Discussion questions

1. What can RFOs learn from the experience of research ethics and integrity bodies in relation to key issues identified?
2. Are there particular ethical issues around participation that are unique to RFOs?



The diagram shows a collection of sticky notes with the following text:

- Researchers need training in participatory processes
- Are researchers/ethics boards forced to do the work of participants? Stakeholder communication is not a typical skill for researchers. True but the consortium could include someone with those skills if citizen/consumer engagement is required
- May need a two stage development of informed consent. One where consent is asked for consultation and then following co-creation of the actual developed protocol
- Offer citizens a voice in reflecting on the research process
- Give voice to citizens in research design
- suggest ways for citizens to be able to reflect on how the research impacts their lives
- Create governance structures that include citizens
- Need for funding organisations to carry out a pre-call ethics assessment to ensure the call itself does not give rise to avoidable ethical problems
- all calls need to include some participatory process/method used
- calls/proposals need a language that is understandable to lay people
- the clear about the purpose of the involvement
- Open mind from the research team means that participants' opinion is as much relevant as research
- respect participantes as experts
- have the resources to involve end-users, including being prepared to handle the unexpected
- Earlier exit of participants; incentives to participate should take into account this possibility
- Industry and research organisations have a different interest/approach to ethical issues
- Ethical issues from the perspective of industry are related to business concept; added value to the product



## Group 2: Innoviris

**PRESENTATION (9 mins)**

**Citizen jury**  
Aim of the pilot and what you have used a participatory process

- Funding program for PRR projects (co-outlets)
- Inviting citizens experts in the evaluation jury for the selection of PRR projects
- Objectives
  - Bring a citizen expertise
  - Bring a new perspective
  - Share in 2018 2 experiments
  - 2019 more challenges: clarify the subject expertise and deal with a differentiated approach.

**Method of participation**

- For each project a pair of 2 citizen experts follow a training path and attend the evaluation as a jury member

**Type of participants**

- People living in Brussels
- People concerned by the strategic goal of the program (Citizen Reference)
- People willing to participate to the evaluation process

**Key ethical (and integrity) issues faced in designing and carrying out the pilot**

- Clarify the sought expertise
- Evaluation on all citizens?
- Deal with a differentiated approach.

**Q&A (5 mins)**

**MIRO WARM UP (2 mins)**

Create a sticky note and write your name and institution on it - move it so that it sits above the group number/name.

**ACTIVITY: IDENTIFYING KEY ETHICAL ISSUES IN THE PILOTS**

Based on the presentation of work that has taken place in the first pilot, what are the key ethical issues that RFOs are likely to face in relation to participation in this area of practice (i.e. evaluation)?

- Everyone in the group add ideas to the board using post-its (5 mins)
- Facilitator to cluster post-its and everyone in the group to use green dot votes to select priority issues (5 mins)
- Facilitated discussion about what can be learned from the experience of research integrity and ethics bodies/experts in relation to key challenges (20 mins)

**Discussion questions**

- What can RFOs learn from the experience of research ethics and integrity bodies in relation to key issues identified?
- Are there particular ethical issues around participation that are unique to RFOs?



## Group 3: VDI/VDE-IT

**PRESENTATION (5 mins)**

**Q&A (5 mins)**

**MIRO WARM UP (2 mins)**

Create a sticky note and write your name and institution on it - move it so that it sits above the group number/name.

**ACTIVITY: IDENTIFYING KEY ETHICAL ISSUES IN THE PILOTS**

Based on the presentation of work that has taken place in the first pilot, what are the key ethical issues that RFOs are likely to face in relation to participation in this area of practice (i.e. innovation projects)?

1. Everyone in the group add ideas to the board using post its (5 mins)
2. Facilitator to cluster post its and everyone in the group to use green dot votes to select priority issues (5 mins)
3. Facilitator discussion about what can be learned from the experience of research integrity and ethics bodies/experts in relation to key challenges (20 mins)

**Discussion questions**

1. What can RFOs learn from the experience of research ethics and integrity bodies in relation to key issues identified?
2. Are there particular ethical issues around participation that are unique to RFOs?

