



opencare

## Deliverable 6.6: Final ethics report

<i>Project Acronym</i>	OPENCARE	
<i>Title</i>	Open Participatory Engagement in Collective Awareness for REdesign of Care services	
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<i>Lead Beneficiary</i>	UBx	
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## Rationale

Opencare has taken to heart a radical and deep approach to ethics throughout the entirety of the project.

Averse to box-ticking logic of certification, the consortium has interpreted ethics as a dimension for continuing reflection upon the project, instead than thinking in terms of adhering.

This is not to say that the consortium has paid little attention to the standard items of ethical oversight: for example the project has designed its own informed consent funnel that has been deployed side by side the most common "terms of service" information on the web platform.

However, where the project has diverged from standard practices is in that it has considered ethics a process rather than a point. The management has reverberated its conversations constantly online in the open, for every stakeholder to be able to check and join the reflections; the internal auditing has been conducted as a peer-auditing by and with the partners and stakeholders; every event has been supported by a dedicated informed consent sharing with the prospective participants details concerning the scopes, goals and means relevant to that specific event, with granular choices offered to the participants.

Ethics, we dare stating, has been part of the very community intelligence that animated the project. A pillar of its strategy, and one of the dimensions on which every conversation measured itself.

## Ethics report

In the second and last year of opencare ethics has developed much smoother than it did in the first year. Partially an effect of having started well, with much investments concentrated in the first months of the projects to establish good practices and to reflect on their meaning for the project and the community; and partially because of a maturation of the community itself, which spontaneously cycled on reflections about its identity, meanings, and goals for action.

However, a major accident happened during 2017<sup>1</sup>. Around 300 online contributors had been able to participate on the portal without being welcomed by the informed consent funnel, due to a glitch in the content management system's handling of the dedicated custom module.

The issue has been discussed at length with the ethical advisors, who have also joined the online conversation to offer public reassurance concerning the adequacy of the countermeasures decided upon, and on the minimal risk of misunderstanding of purposes by the affected contributors thanks to the redundancy of information across several sections of the platform.

Both public communication about the issue, and direct connection with the affected partners have been timely, and the missing consents are being recovered at pace, with no reports of misunderstanding not distress by the affected contributors.

Thus, the accident can be considered resolved.

This has informed conversations with the project partners, and the communities about the upcoming GDPR, its meaning and the most relevant strategies towards compliance.

Further ethical considerations have been reported in the extended version of deliverable 4.5<sup>2</sup>, which includes reflections about the online interactions and their social contract, and in deliverable 1.6<sup>3</sup> that focuses on the sense making of our original promises, and the

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<sup>1</sup> <https://edgeryders.eu/t/a-problem-with-the-ethical-consent-funnel-and-how-to-solve-it>

<sup>2</sup> <https://drive.google.com/file/d/oBov8cXoWOo5zdzBxSzdrLWtoRjQ/view>

<sup>3</sup> <https://drive.google.com/file/d/oBov8cXoWOo5zQzdxNTQybi1RMEU/view>

project delivery on them, by the communities we have come in touch with.