



opencare

Deliverable 6.5: Ethics guidance report

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<i>Reviewer(s)</i>	Guy Melançon	University of Bordeaux
	Alberto Cottica	Edgeryders
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Deliverable 6.5

Editor – Mara Manca

Reviewed by – Marco Manca, Antonio Vittorino Gaddi, Mario Falchi for Tim Spector.

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"Even a purely moral act that has no hope of any immediate and visible political effect can gradually and indirectly, over time, gain in political significance."

Václav Havel (Czech philosopher, political dissident)

As OpenCare approaches its second year, it is time to review its consortium and community's activity so far, as to offer an opportunity of reflection and improvement to the management and the consortium members.

To frame the ethical discourse around OpenCare, it is worthy highlighting the words proposed by one of the community members who got engaged by the project, "a Copernican revolution, we have long been waiting for"¹, and keeping in mind the reflections about the nature of the two defining concepts behind the project, "open" and "care", as described in the living document "OpenCare Playbook"².

Hence, the social contract of OpenCare with its community is not a simple one, and it requires to be analyzed in its multidimensional realm of existence: (formal) informed consents to information sharing and procedures; (unspoken) expectations, projections, and trust; governance and fluidity of management; exploitation and redistribution.

The following will be divided in sections reflecting the above mentioned "dimensions", to offer an "as pragmatic as possible" evaluation of the state of the project after its first year of activity.

¹ <https://edgeryders.eu/en/opencare-il-mio-personalissimo-startup>

² https://playbook.opencare.cc/ezio_manzini_about_opencare_project.html

1. (Formal) informed consents to information sharing and procedures

"Ethics change with technology."

Larry Niven (American sci-fi author)

OpenCare is a H2020 funded project, under the action "Collective Awareness Platforms for Sustainability and Social Innovation" (CAPS)³.

To meet its goals, OpenCare is running an online platform to host EU citizens' conversation about care needs, worries, and personal experiences, or ideas to work within the current welfare ecosystem, whether as practitioners, beneficiaries, or stakeholders.

OpenCare kicked off while the EU Parliament and Council were in the process of updating their "EU General Data Protection Regulation", updates^{4,5} that entered into force on 24 May 2016, albeit they shall apply from 25 May 2018, after the project conclusion. Hence, it has been made a priority by the consortium to ensure that the project would be able to uphold the new rules, in principle at least (as the National law transpositions are not yet available).

In March 2016 the Consortium adopted a consent funnel to serve as informed consent for the online platform. Rather than assuming the form of a "legal language contract" with the participant, the funnel, documented in the "Data Protection Guidelines OpenCare", consisted of 8 questions that would force the newcomer to read and reflect about the risks arising from sharing information by joining the conversations, in comparison to other experiences the subject may already have, and to consciously accept that these are bundled to the possibility itself of running a community experience like the one facilitated by the project.

One minor glitch in the organization emerged when it became apparent, after the approval of said funnel, that the efforts declared to this end had been devoted to the design of the method, but not its implementation, a possible crisis that was resolved by a joint best effort by SCImPULSE Foundation, which implemented the funnel in a Drupal module compatible with the CMS on which OpenCare is hosted, and the Edgeryders Ltd, which took care of uploading and proper triggering of the questionnaire for newcomers.

³ http://cordis.europa.eu/project/rcn/198824_en.html

⁴ http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.L_.2016.119.01.0001.01.ENG&toc=OJ:L:2016:119:TOC

⁵ http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.L_.2016.119.01.0089.01.ENG&toc=OJ:L:2016:119:TOC

This episode highlighted both a weakness of the consortium, which we recommend working on, namely a lack of communication among partners that gave rise to the mistaken conviction that somebody-not-me would have taken care of a step following up the study and design of a new procedure.

However, it highlighted a strength, which the project should try to nurture and make as visible and accountable as possible, in the ability to enroll volunteers who would plug in when needed and enable efforts beyond those originally envisioned.

From an ethical point of view, it is worth stressing how this orchestrated unforeseen pitfall response symbolized the strong commitment of the consortium to an accountability approach to the relationship towards activities, rather than to a responsibility, bureaucratic form of operation that could have betrayed the purposes of the task.

Analyses of the ongoing online conversations, and further reflections by the consortium members lead to the decision that in its current implementation the platform run by OpenCare is akin to a *micropublication* service, rather than a social media. Furthermore, conversations do not target specific profiles, nor the platform invites or especially supports medical data sharing, which is recommended against in the consent funnel. As such, no medical ethical committee has been able to pose a recommendation concerning the platform, judging it beyond their mandate.

OpenCare has also published a freely available data management plan, reachable from their homepage⁶ by anyone, registered or not.

However, the formal side is not limited to the online interactions. Every partner in OpenCare is running also real-world activities that are meant to engage with relevant stakeholders and that should, according to the project plan, enter a virtuous cycle of feedback with the online domain. Whilst handling the traditional part of the formal duties for such physical encounters is fairly straightforward, and each partner has adopted appropriate informed consent to image/video capturing and publication, the task of facilitating, and sometimes mediating a representation in the online conversation of physical people and their ideas, is somewhat closer to the proxying exercised by an attorney, and falls beyond the scopes of standard consents. The current recommendation to every partner involved in this activity is to include an explicit description of what this would entail, and where the boundaries of this activity would be drawn (one shot

⁶http://opencare.cc/info_privacy_terms.html

posting, mediation of conversations by contacting the represented individual/originator of the represented idea, subscription to mailing lists or other bundled services, ...), seeking an explicit approval/dismissal of the offered proxying.

2. (Unspoken) expectations, projections, and trust

"If a problem is irreversible, is there still an ethical obligation to try to reverse it?"

Chuck Klosterman (American author and essayist)

Being aware of one's social contract reigns over the ethical reflections of any human activity. Social contracts are only poorly reflected in the formal and explicit agreements that are woven around them. Unspoken expectations, projections of hopes and fears, and ultimately trust, are the pillars on which actions ruled by incomplete contracts^{7,8,9}, like OpenCare, thrive. Intriguingly, this is deeply interlaced to one of the core activities of OpenCare, as the effort of leveraging digital ethnography to extract an intelligence from the community conversations can be seen an attempt to bring to consciousness all the unspoken(s) bringing the stakeholders and community together.

Some rather interesting choices have been taken by the project on this dimension.

One that is fairly striking, and that has been subject of vivid debates among the partners several times during the first year, is that of identifying people as agents, as opposed to users, which translated in a "brutalistic" platform design, ignoring any consideration on UX or appeal, as a statement about the scopes and roles in OpenCare. Some partners have repeatedly expressed frustrations with the steep cost of attracting and retaining people around conversations that comes of the aforementioned design choice. However, the responsible partners have proposed a convincing argument that this distress would be resolved by changing the execution of engagement activities, moving them towards the model of

⁷ Grossman, Sanford J.; Hart, Oliver D. (1986). "The costs and benefits of ownership: A theory of vertical and lateral integration". *Journal of Political Economy*. 94: 691-719. doi:10.1086/261404.

⁸ Hart, Oliver D.; Moore, John (1990). "Property Rights and the Nature of the Firm". *Journal of Political Economy*. 98: 1119-58. doi:10.1086/261729.

⁹ Hart, Oliver (1995). *Firms, Contracts, and Financial Structure*. Oxford University Press.

community management¹⁰. Awareness of the need to adopt this alternative strategy for the online platform has been growing within the consortium over the second half of the year, as the partners reflected on the community growth, and representation of heterogeneous interests. In facts, despite successfully reaching the milestones, there is unanimous agreement within the consortium that still more untapped potential lies in wait of finding a matching onboarding strategy. In the next few months we expect an effort by the partners to adopt a more fitting style, following the new understanding of the implications of the agent/owner-by-design style choice, accompanied by essential conversations about how to absorb the overhead of this new approach to execution of engagement after the funding will cease.

It descends from the above-described engagement dynamics, that OpenCare has to reflect on the proactivity of onboarding and moderation, to avoid that in this post-truth age^{11,12,13} the conversations on the platform get skewed around a priori biases of self-selection. How should the moderators react to the information extracted by network and ethnographic analyses that migrants are perceived as a destabilizing factor for welfare? Or that any other news misrepresentations were reverberated in the online conversations? Has moderation and onboarding the role of ensuring a certain level of diversity is represented on the platform and according to what metrics? If the platform is meant to serve as a soil to nurture community-distributed intelligence, what degrees of curation are due and legit? Open questions, that have a huge importance far beyond OpenCare, and on which the consortium keeps observing and interacting with other stakeholders touched by the same worries to learn as quickly as possible.

Another unique trait of OpenCare falls under this dimension. The project members manifested in their proposal the intention to "work-out-loud", or to put it in explicit words to make the working and reflections of the consortium transparent to anyone. The consortium published the winning proposal on the web under CC-BY, and made the space for

¹⁰ <http://edgeryders.eu/sites/edgeryders.eu/files/OpenCare-%20Methods%20and%20tools%20for%20community%20engagement.pdf>

¹¹ "Post-Truth Politics". Grist. 1 April 2010. Retrieved 11 July 2016.

¹² Tom Jeffery (26 June 2016). "Britain Needs More Democracy After the EU Referendum, Not Less". The Huffington Post. Retrieved 11 July 2016.

¹³ "The post-truth world: Yes, I'd lie to you," The Economist Sept 10, 2016

debate and coordination of the research group¹⁴ open to the web, licensing its content under CC-BY. This is a very powerful tool, as we can learn from other fields where unspoken contracts rein activities, like medicine. In facts, claims in medical practice pose a huge burden, both economic and motivational, on care providers, and they have been subject of research for decades now, offering solid evidence that most conflicts raised from lack of transparency/communication that in turn caused a divergence of expectations¹⁵. A theory supported by well-established observational¹⁶ and experimental¹⁷ evidences.

However, despite a positive disposition of the consortium members towards an apparently advantageous practice, the consortium during the first year seems to have slowly abandoned the practice, or rather to have moderated its use, to later slowly take it back up again. Analyzing the historical trends on the platform, it would seem that the negative peak was reached around summer 2016, and that the trend became positive again in the middle of autumn. As of January 31st 2017, the debate/coordination space had 407 posts, wikis, tasks, events and 1,907 comments, for a total of 273K words. This is of the same order of magnitude as the community space (411K words).

It is not possible to draw statistically sound conclusions due to the singularity of the observation, but it is striking how the negative peak happened around the "crisis" that followed the decision by the Commission that the consortium would not be authorized to grant support to grassroots projects, unlike what stipulated in the description of the action signed with the contract. The centrality of this granting mechanism to the engagement strategy¹⁸ caused the consortium to shake, and a few other activities to be significantly delayed in order to adapt the strategy to the new conditions. As would be expected, this transformation and change of pace have not been symmetrical across the consortium, and attrition arose among some partners, which was reflected in harder communications on the research platform (which is public and known to the community, as proven by the fact that

¹⁴ <https://edgeryders.eu/en/opencare-research>

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<http://jamanetwork.com/journals/jamainternalmedicine/article-abstract/612300>

¹⁶ <http://jamanetwork.com/journals/jama/article-abstract/414233>

¹⁷ <http://annals.org/aim/article/745972/liability-claims-costs-before-after-implementation-medical-error-disclosure-program>

¹⁸ <http://edgeryders.eu/it/opencare-research/the-opencare-engagement-strategy-at-a-glance>

community members occasionally "jump in" and take part in the research team's reflection¹⁹, an effect of the work-out-loud approach). Towards the pacification of these conflicts, the consortium decided to exercise its content moderation right, and agreed to remove some of the threads, despite being resolved. This is all but surprising, as the consortium became aware during those events of the fact that real-time transparency can sometimes, in a network with delayed reactions, generate a propagation and amplification of tensions. In facts, in many real-world networks connections are pruned under stress to avoid an uncontrolled diffusion of the problem. However, the issue has been dealt with as a one-of-its-kind, while it would be recommendable to work out some principles or instructions about the maneuver, to make even this partial obfuscation a decision as transparent as possible. The re-adoption of radical transparency is a work in progress, and would be facilitated by clarity of rules of curation/moderation on this front. Failing to do so could, in the long term, or should other episodes appear, dilute the virtuous trust-nurturing effects of the work-out-loud policy, while also reverberating on the relationship of the community with the consortium. Met and unmet expectations have large effects on the dynamics of community exercises, as placebo/nocebo effects has in medical therapy, and should not be regarded as mere administration issues.

¹⁹ <https://edgeryders.eu/en/opencare-research/slides-presentation-methods-and-tools-for-opencare>

3. Governance and fluidity of management

"The only crime is pride."

Sophocles (one of three ancient Greek tragedians whose plays have survived)

A challenge common to many complex projects, whose division in tasks and work packages results in a convincing rhetoric exercise but fails to encompass the many interdependencies among activities and partners, not just in terms of planning, but of expertise and know-how. OpenCare has so far been very successful on this dimension, not one partner escaping from the consortium to pursue its own goals and stakes by trying to interpret the description of the action to the letter. Rather, the partners in the consortium have been fiercely discussing, sometimes until the point of violently agreeing on a course of action, bringing all their stakes at the table, and negotiating until a viable solution emerged that could be accepted by everyone involved.

In a real world, void of the illusions of perfection of plans, and of continuing uneventful agreements, this is the best approach to collaboration one could expect to observe, and it has emerged a sufficient number of times (including during the aforementioned crisis) to be considered more than a statistical fluke.

Hardly any recommendation to improve this approach of trustworthy, humble, and purposeful collaboration can be offered.

4. Exploitation and redistribution

"Remember that it is not you who supports the root, but the root supports you."

Apostle Paul (from the Letter to the Romans)

In the first year OpenCare hardly had any chance at *exploitation* as the reader could think of it. However, great value is generated in mobilizing such a large community, and tensions to channel it have already emerged in some instances. For a number of very good reasons the public image of OpenCare has been scattered over a number of identifiers (OpenCare, Op3nCare, OpenAndChange,... to mention a few) that could be considered akin to spin-offs, as identity value is concerned. An identity value that is perceived by the community gathering around it²⁰, and that at the moment is protected by the stubborn decision to avoid to transform it in a coded label: anything that is pushed forward by community members is to be taken as their understanding and definition of care, and hence dignified to be *opencare*.

Although other activities^{21,22} exist under the name *opencare* and pre-date this project, the identities created as spin-offs are rather strong²³ and easy to identify thanks to the logo shared with the official EU project. However, it is not easy to identify what licenses regulate the logo and "brand", and who is their "owner", for a newcomer to the project/community, and it is only by assumption that a visitor is lead to decide it is most likely owned by Edgeryders LGB.

Furthermore, although it is fairly clear and well described how to become involved with the community, and how to participate to the experience, it is not documented what rules are at least recommended for initiatives that could extract value from having joined, and the CC-BY licensing of the content on the platform only instates the obligation to acknowledge creators "by mention" but automatically grants rights to reuse, also commercially, without further negotiations. Whilst it is common to feel that a copyleft kind of approach, where anyone doing something is welcome with no worries about distribution of profits, would be ethical by avoiding entry gaps to the doers, this could actually ignore the gaps in expertise between observers and the community, and ultimately leave the community in the wild for exploitation by third parties.

²⁰ <http://edgeryders.eu/es/comment/25683#comment-25683>

²¹ <http://www.opencare.it/en/>

²² <https://www.opencare.com/>

²³ <https://edgeryders.eu/en/op3ncare/helping-one-another-to-discover-what-is>

This is an aspect we recommend the consortium takes quick heed of, and while researching inclusive and accountable models of distributed collaboration, that it issues a set of recommendations, and suggested paths for any fall-out initiative to hold truth to the social contract binding the community together.

*"Life can only be understood backwards; but it must be
lived forwards."*

Søren Aabye Kierkegaard (Danish philosopher)