



openecare

Deliverable 1.6: Peer-auditing of the project, and indication on how to work-around failures and pitfalls

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| <i>Project Acronym</i> | OPENCARE | |
| <i>Title</i> | Open Participatory Engagement in Collective Awareness for REdesign of Care services | |
| <i>Project Number</i> | 688670 | |
| <i>Work package</i> | WP1 – Design and evaluation of community based health/social policies at scale. | |
| <i>Lead Beneficiary</i> | Scimpulse | |
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| <i>Dissemination Level</i> | Public | |
| <i>Contractual Delivery Date</i> | 31/08/2017 | |
| <i>Actual Delivery Date</i> | 07/12/2017 | |
| <i>Version</i> | 1.0 | |
| <i>Status</i> | Final | |

Summary

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Rationale

Validation is often met with confusion.

«... after all, it would be a fair waste of time to check such things after delivery.¹»

In facts, it is due to disclaim between *validation* and *verification*. The latter is concerned with the question of whether what has been delivered by a project corresponds or not to the specifications announced during its design phase, whilst validation focuses on whether its end effects, its meanings once whatever has been delivered has come to fruition, meet the declared goals that justified the approval of the project in the first place.

The reasons to include validation in a process can be multiple, but the most important one is the consciousness of operating in a complex environment, with only limited access to prior information.

Under such circumstances, any however deep and well-thought plan, would just be an ingenious attempt at giving a shape to prejudices and partial models. Equivalent to experimentation in the lively cycle of innovation, validation offers the opportunity to estimate how far off the original expectations a project has ended at any given time, and how to mitigate the disturbing conditions to meet the original goals.

In the case of OpenCare, verification is largely performed by each and every partner, as it is part of the reporting requirements of any H2020 grant agreement. Validation however is often downplayed by EU funding schemes regulation, as pointed by ECA's Gabriele Cipriani², for a number of relevant reasons connected with the complexity of accountability in multi-actor actions.

The Consortium has decided to adopt validation procedures recursively along the life cycle of the project, as one of the tools to collect feedbacks and collective intelligence offline, and this report is a snapshot of this activity.

¹ As commented by [Andrew Barham](#) of PWC, explaining the role and methods of internal auditing.

² Cipriani, Gabriele (2010) *The EU Budget: Responsibility without accountability? CEPS Paperbacks*. November 2010 - ISBN 9789461380531

Evaluation

Running a peer evaluation of OpenCare we were first faced with the need to identify on which dimensions to engage our stakeholders and partners when trying to obtain their judgement- about whether or not the project is in due course to meet its goals.

In a pledge to the utmost transparency, we have decided to stick to very words used to describe the project when submitted for funding, specifically to focus on the detailed objectives describing each work package. Fundamentally, we treated the text contained in the proposal and grant agreement as OpenCare pre-registration, in line also with the commitment to the public expressed when we published the text on the web page (<https://edgeryders.eu/t/opencare-proposal/4860>) for everyone to read.

Hence, while interacting with communities as part of our off-line efforts and on-boarding, our communication slowly evolved along a spectrum that started with a shared effort at making sense of what our actions would look like and mean for them, to evaluating whether their output met these emerged expectations, as the project developed and met the complexities of reality.

Following, we succinctly report the consensus extracted from the conversations, which are to be taken as a snapshot, not a definitive result.

1. To offer a set of tools and strategies for online and offline community conversation and users' reflection.

OpenCare has been prolific with strategies documentation. A playbook has been published early on (<https://playbook.opencare.cc/>) accompanied by the rationale and documentation related to the serious playing sessions (<https://drive.google.com/file/d/oB7Qizz3lKLItZGZTWDhTMWlJVfU/view>).

However, the above mentioned are little known by communities at their first engagement with OpenCare, which is reflected by the visitor statistics. The most effective and recognized strategy is the « working out loud » approach, which exposes most of the inner working, and steering of the project to the general public, and works as a continuing appropriation mechanism.

The evolution of the online platform <https://edgeryders.eu/c/opencare> has been recognized as a significant effort towards online engagement by most of the stakeholders. Features that would be further welcomed are conversation playback, conversation thread-crossing detangling or cross conversation threading, and mining by graphryder, that the users seem unanimously convinced would help extracting more value, easier, from the platform.

2. *To promote public awareness of the proposed infection of care giving from the hackers' culture, to investigate the feeling and perceived roles of relevant stakeholders, to identify trade-offs and regulatory vacuums that might affect the future of care.*

EHFF/SSE has produced an extensive survey of practices in the field our exercises with the community identified as open care, and has emphasized the role evasive entrepreneurship http://swopec.hhs.se/haechi/papers/haechi2016_002.pdf, a concept first described by Coyne CJ and Leeson PT in 2004³, and later associated to institutional innovation by Elert N and Henrekson M in 2014⁴. The concept has a huge appeal on our stakeholders and partner communities, which often share their frustration about the experience of competing against incumbents within the limits of current regulations. A tension however exists between the informal, evasive strategies projects are keen to follow at the beginning, and their desire to bring and formalize change for all. This transition is still largely unmapped, and the request for mentoring and support accelerates with the growth of the community. A reflection on scaling up support to this transition from informal to formal is strongly called for.

3. *To proactively engage users and stakeholders in experimenting with the tools and platforms produced by the consortium, promoting the role of citizen experts, champions, and gathering wisdom about the ecosystem from conversations and misuse.*

WeMake, building on their model of action, has been a prominent player in arranging hands-on activities. A calendar of past, present, and future event related to OpenCare is available here <http://wemake.cc/opencare/>. « Master of networks » events have been organized by Edgeryders and UBx attached to all the consortium gatherings, granting a limited public access to mentored use of graphryder, participating to the analysis and sense making of the online digital ethnography of OpenCare. SCImPULSE Foundation has arranged small events of simulation and self-reflection for projects at various stages of maturity that aimed at having an impact on the care landscape, and has invested a lot of time to meet the communities on their territory and during their own meetings. The wisdom and knowledge gathered through all these activities has in turn informed either the platform or the evolution of the off-line activities, lead to a maturation of the mentoring format and the strategies to support partner and stakeholder projects. None of the afore-mentioned strategies, neither online nor offline, has reached virality, however their organic growth is based on solid roots, and low risk.

³ Coyne, C. J., & Leeson, P. T. (2004). *The plight of underdeveloped countries*. Cato Journal, 24(3), 235–249.

⁴ Elert, Niklas; Henrekson, Magnus (2014): *Evasive Entrepreneurship and Institutional Change*, IFN Working Paper, No. 1044

4. *To provide a layer of abstraction for participants and users to reflect on their goals and roles.*

The online platform setup and managed by the Edgeryders offer a layer of community wide conversation and reflection. However, most of the ongoing exchanges focus on pragmatic expertise sharing and on discussing workarounds to common barriers. SCImPULSE Foundation is engaging communities in one-on-one conversations to let them take a step back and evaluate the meaning and values behind their moving reasons, evolution and execution. It has been discovered during OpenCare that the value of this kind of intelligence is underappreciated by the stakeholders, at baseline, maybe due to a bias towards action rather than reflection. Consequently, this goal has transformed into one of need creation, by educating the communities to the strategic value of such abstraction and thinking.

5. *Build a community to imagine and design the future of health and social care, and their own role in it.*

Community building is an exercise primarily happening online. However, as the tone and topic of conversations tends to be ones of action planning and expertise sharing, in the context of local and hyperlocal initiatives, a true feeling of community fails to emerge and be affirmed. Proposed explanations of the above range from the sparseness of conversations, to the lack of a unanimous plan or ideology that everyone feels to be adhering to. Very different practical and ideal issues are proposed by community members at the edges in North of Europe, the Mediterranean region, and the American (mostly US) representatives, sharing a feeling of displeasure with the way authority sort out problems, and a will to take matter in own hands, but in political, economic, and social contexts too far away to merge in one identity. Hence, as far as the goal is interpreted as to offer a space for conversations about desired change and actions, the project is largely succeeding. If emphasis is put on the aspect of building a community, more efforts should be invested in building a consciousness, a unifying ideology and utopia (with reference to Ricoeur's work⁵), to bind all the partners in one being, rather than just federating them.

6. *Make sense of the diversity of experiences and approaches by running ethnographic research on the Edgeryders interactive platform where the discussions take place.*

This is work in progress. Mixing ethnography with quantitative network analysis is a matter of research, and despite promising, one cannot stress enough that the very nature of research is to deal with the uncertain. The promise of the method is solid, as documented by the output in scientific literature (https://link.springer.com/chapter/10.1007/978-3-319-50901-3_4), however the impact on the *making sense of diversity* has yet to be delivered, as most of the stakeholders expect emphases rather on identifying common

⁵ Paul Ricoeur. *Lectures on Ideology and Utopia*. Columbia Univ Pr (1986). ISBN-13: 978-0231060486

strengths and challenges, rather than understanding diversity. Hence, more resources should be invested in creating an understanding of this effort, and in explaining the advantage of capturing uncertainty and diversity.

7. Facilitate the community in selecting ideas for care services to be prototyped, and in evaluating the results of the prototyping activity.

The reactions to this point varied widely. Closer partners and stakeholders felt a clear influence of the moderation and mentoring offered by OpenCare in selecting their train of action and shaping their goals. It can be said that OpenCare had a strong maieutic footprint listening to their opinions. However, as mentioned above, OpenCare has all but gone viral in its outreach, and most communities at the edges of our reach, or first contact stakeholders, tend to identify OpenCare's impact mostly with the strengthening of ongoing activities, rather than the acceleration of new initiatives. Indeed, except for a handful of examples, most visible of all OpenRampette <http://rampette.opencare.cc/>, OpenCare's impact may take longer than the life of the H2020 funded project to deliver a significant impact on this dimension. The community looks to OpenVillage <http://openvillage.edgeryders.eu/> with great hopes.

8. Prototype 2 to 4 ideas around innovative care services, co-designed by OpenCare's smart community. The close link created between hackers, caregivers, and people in need of care, technology artifacts and design tools allows creativity to flow and quick prototyping cycles to happen.

No project is felt as « co-designed by OpenCare's smart community ». Not even OpenRampette, which is (and rightfully so) the product of the local intelligence in Milan. Maybe we had been naive in our initial wording, or this is an impact that is yet to follow, but every initiative acknowledges in the OpenCare global community a mean to tap from general wisdom and expertise, and to evaluate its own operation, but does stress the local origins of its own project. Further to OpenRampette, the design toolkits of OpenCare has been useful for rehub <http://www.rehub.pro/>, hubotics <https://www.youtube.com/watch?v=7c5So1mrszg>, and SoundSight <https://www.youtube.com/watch?v=lq7ku4uwmbI>, all projects that acknowledge the impact of reflecting with WeMake and SCImPULSE about their strategies and goals.

However, a step back should be taken to reflect about the expectation of shaping and selecting projects within the opencare community (as « on the platform »), and if reinforced in this intention after the exercise, the consortium should rethink how to balance locality and globality to this end, consequently informing a new style of community management.

a. Learning how to move an online conversation from perception of need to solution design.

The general perception of this is negative. A lack of adequate online tools integrated with the platform to cowork on design concepts, or to survey, and A/B test is usually pointed out. The platform is geared for

conversation, and the transition towards solutions requires a migration offline.

b. Crowdsourcing design inputs, tapping into the community's diverse knowledge.

An undisputed success! There has been no interaction where this was not mentioned has an added value of working with OpenCare.

c. Presenting the users with early prototypes for evaluation and contribution.

This activity happens offline, locally, as the engagement targets the communities that brought up the need and that would recognize the solution as a common. An underappreciated activity in the eyes of the online community, but a very intense experience offline.

d. Making visible to the community the financial and technical constraints of moving from idea to prototype.

A difficult one to evaluate: most stakeholders are well aware of the financial and technical struggles. Here conversations focus on evasive entrepreneurship and commoning⁶. OpenCare is not acknowledged as a prominent contributor of awareness and wisdom on this, each initiative aiming to tap from practical expertise by other peers on their online conversations.

e. Taking into account other limiting factors like age, culture, language, interoperability with existing solutions and standards.

Reflections on, for examples, language have been rather deep, and public <https://edgeryders.eu/t/fellowship-post-3-hidden-structures-of-language-and-assumption/6973>. The lack of virality of OpenCare content means that awareness of this is somewhat limited.

f. Iterative testing and debugging.

The same barriers mentioned above for the point *a* are relevant here. Hackers and makers have a strong experience in this dimension, and their favourite tools, and they do not report that OpenCare should invest in this dimension.

9. Survey existing collective intelligence projects in the care sector:

None of the contacted peers seems aware of this activity. Neither do they know that a survey had been conducted, nor they are aware of where the results will be made available and discussed, although they expect the platform would offer pointers in due time. A campaign of engagement on the platform would be welcome.

⁶ Peter Linebaugh. *The Magna Carta Manifesto-Liberties and Commons for All*. University of California Press(2009). ISBN: 9780520260009

a. Assess what features of care programs in Europe can facilitate policy adoption

The peers would welcome a layperson accessible report on the topic, rather than an academic analysis.

b. Investigate the impact of accountability and ownership on sustainability and scalability of welfare participatory design

Every offline exercise has included sessions of reflection on this topic, and a map to navigate through advantages and pitfalls when organizing an initiative would be highly palatable to almost every stakeholder of OpenCare.

The research questions are both empirical, (I) to what extent have collective intelligence projects (including prediction markets) been used in the care sector in Europe, (II) what are the features of these programs, and policy oriented (III) what will make a collective intelligence project successful (e.g. which policies will facilitate the emergence of successful projects), (IV) to what extent existing projects are scalable. The field studied will be the European health care sector where bottom up, collaborative projects might provide new solutions, providing real value for society.

Stakeholders expressed curiosity for these topics, but many had little information about what OpenCare is doing to investigate them. They would like to be engaged more in the gathering and analysis of that will develop OpenCare in this dimension. They would welcome more expert interaction on the platform, and are curious to understand how this body of work will continue living after the end of H2020 funding.

10. Support ethnographic coding with (semi) automated methods and dedicated visual interactions.

Not many have played with the online dashboard <http://graphryder.opencare.cc>. However, thanks to the « Master of networks » workshops, and several posts on the online platform, the community has developed a palate for this kind of approach and a vision for where it is headed. The paper « *Semantic social networks: a new approach to scaling digital ethnography* » by Cottica A et al http://www.academia.edu/33962048/Semantic_social_networks_a_new_approach_to_scaling_digital_ethnography could be better advertised, and the communities would appreciate the existence of a lay person, annotable version.

11. Support community managers in: supervising exchange dynamics, point at salient themes or issues discussed on forums, identify all involved actors and their roles.

Mostly too technical to extract any relevant evaluation by the peers engaged in OpenCare. Community management would seem to adhere to Clarke's third law: when it is sufficiently well performed, it disappears from everyone's

consciousness and becomes like magic. If one holds true the aforementioned, then OpenCare is performing an excellent job on this dimension.

12. Produce dedicated methods and tools, improving on the state-of-the-art where necessary.

Again very difficult to engage the stakeholders on this dimension, when most of them had been almost oblivious to the community management happening at all. When challenged to reflect on the inconsistency of this perception against the results published in https://link.springer.com/chapter/10.1007/978-3-319-50901-3_4, the conclusion reached has consistently been that evidently the project is performing really well, although the evaluation of this challenge still felt out of their depths.

13. Produce prototypes embodying the proposed methods, and insert these tools into an integrated working environment (for community managers and/or for ethnographers).

The unanimously positively welcomed new version of the online platform seems to point out to a success of OpenCare on this dimension.

14. Develop a self-reflecting approach to all ethical concerns regarding OpenCare

Ethics is commonly misunderstood as a boring effort, mostly focusing on *don'ts* and is, as such, not always the hot topic of community conversations. When engaged with a pragmatic approach to ethics, as it should be, however the perception of its input to an initiative radically changes. Most stakeholders end up recognizing that ethical reflection contributes significantly to informing one's strategy. OpenCare is acknowledged to have put significantly more attention on ethics than known comparable projects, and above all to have invested in mentoring partner projects for a new approach to it.

In conclusion, the evaluation exercise gives a largely positive feedback about OpenCare, and its delivery on the promised goals.

There are items on which more attention could and should be invested, as in reference to points:

- 4, it would be worth investing more efforts in educating about strategy making, for example by expanding the core wiki-style literature repository (playbook⁷) that we wish the community would appropriate, by gathering and commenting relevant resources, and examples, from the universe of grassroots experiences;
- 5, it would be worthy reflecting on whether an emergent sense of community is indeed a relevant objective of OpenCare, not in conflict with its attention for local solutions against the rhetorics of scale, and

⁷ <https://playbook.opencare.cc/>

if so investing in the necessary community management to nurture such a feeling globally;

- 8a and 8f, it could be worthy offering better documentations on the technical aspects of contributing features and third party's functionalities integration to the platform and the relevant regulation/governance, something inspired to BioDynamo's developer guide (<https://github.com/BioDynaMo/biodynamo/wiki/BioDynaMo-Developers-Guide>), or outright APIs and SDK;
- 9 as a whole, it could be worthy investing more on the online interaction between EHFF and the gathered communities, and devoting some extra efforts in the production of a lay person version of the OpenCare outputs on this dimension, to facilitate the offline engagement as well.

The above is not to be interpreted as a prescriptive and exhaustive list of interventions, but just as a recollection of the recommendations offered by the evaluators. Better solutions are possible, or the relevant partners may decide to interpret the feedback as the result of a misunderstanding, investing rather in clarifying communication, than in outright patching and adapting strategies.

Furthermore, as it will strike the readers, there are issues in which shortcomings have been identified (for example point 6) but towards which no recommendation has been expressed by the stakeholders involved in this exercise. This could be seen as their lack of sufficient expertise to identify a way through, or a suggestion that the pitfall is common to the state of the art and could as well be an insurmountable limitation at present.

The present report is meant to be material for reflection towards the concluding months of OpenCare, as the H2020 funded project, and its continuation later on as a common initiative.

Let's boldly go where no one's gone before.