



Join Us to Optimize Health Through Cohort Research

Deliverable 7.4: Experiences as a young consortium

Version 1.0

This project has received funding from the *European Union's Horizon 2020 research and innovation programme* under grant agreement No 101006518.



Project Name	Join Us to Optimize Health Through Cohort Research (JoinUs4Health)
Project No.	101006518
Project Type	Coordination and Support Action
Project Duration	01/01/2021 – 31/12/2023 (36 months)
Project Website	https://joinus4health.eu/
Project Platform	https://platform.joinus4health.eu/
Project Coordinator	Birgit Schauer (UMG)
Funded under	Grounding Responsible Research and Innovation in society with a focus on citizen science (SwafS-23-2020)
Work Package	WP5 Formal and informal science education
Deliverable	D7.4: Experiences as a young consortium
Version	1.0
Date of Submission	30-04-2023
Authors	Birgit Schauer, Johanna Dups-Bergmann (UMG)
Contributors	Tabea Troschke (UMG), Ana Barbosa Mendes (EUR)

EUR: Erasmus University Rotterdam; UMG: University Medicine Greifswald

Summary

This is an extra Deliverable (D7.4), which was defined as part of the mid-term review. The aim is to capture experiences of the consortium in implementing the project to date (as of Month 28) and to convey these lessons learnt to future consortia facing similar scenarios.

This project was, and is, a learning process, a path we follow together, sharing experiences with the aim of developing our approach in a co-constructive manner along the way, whilst learning from one another. On the one hand, our work contributes to reflections on how to make research more responsive, relevant and trustworthy for society, and on the other hand, provides a concrete case study to explore to what extent our proposed approach is practical and has impact on the academic praxis.

Three years is a short amount of time to (co-creatively) design an online platform, build an active (online) community and mobilise potential volunteers, especially early on when the concept and potential applications may still be unclear. Additional external and internal obstacles may occur, which can throw the project off course. Close communication with the project officer is crucial to work jointly towards making the most out of challenging situations.

Experiences as a consortium

- Several partners experienced problems when recruiting staff due to various reasons. In addition, sickness related leave led to further unexpected losses in productive hours. Consequently, partners continuously worked under high pressure given the need to adhere to tight timelines. Therefore, little space was available for revisiting the assumptions that underpinned the decisions made when designing and implementing the project.
- The way the project was planned in terms of tasks and deliverables was in tension with the Responsible Research and Innovation (RRI) approach. While the project aimed to develop a methodology rooted in RRI, we failed to plan for using RRI as an approach for the development of the platform.
- The scope and overall goal of the project were not commonly envisioned by all partners. The project had the ambition of engaging cohort participants, citizens and other groups of societal actors (i.e. policy makers, business/industry, non-governmental organisations, education community) in a more co-creative manner, so as to make cohort research more sensitive to societal expectations and concerns and to promote equal access to science. While the project used the cohorts as its context, it did not limit itself to it. Indeed, it aimed

to have wider impact, by influencing education, rewards system and other institutional mechanisms in the cohort institutions. However, discrepancies occurred since some partners saw the cohorts as central to the project and its goals, whilst others believed the platform should be the focus and that the sphere of influence for the project should be wider than the cohorts.

- Some partners, particularly the cohort partners, had a more instrumental view on citizen science and the goal of our project. Therefore, we spent considerable time trying to find common ground regarding the goals of the project. That tension can already be seen in the project proposal: One of the main hypotheses of the project includes fostering interest in science and promoting science in the region. It was further hypothesized that creating more tangible value of cohort research to the local population may enhance the preparedness to follow the cohort's invitation for randomly selected individuals to take part in medical cohort examinations. Therefore, that tension between participation and the deficit model in public engagement was there from the beginning and could not sufficiently be resolved in the project through deliberation.
- Methodological development activities were disconnected from the working of the platform, partly because of the time constraints in platform development and partly because of our difficulties in attracting active users.
- While the project aimed to enact institutional changes in cohort institutions, it did not have a clear pipeline to ensure those changes would be implemented and taken up.
- Employing a junior person in the role of "methodological advisor" within a consortium that was composed mainly of post-doctoral researchers created resistance in discussions about methodology at times.

Lessons learnt

The aim of RRI is to change the way research is conducted in the sense of making research more responsive to societal needs, values and concerns through developing interactive methodologies. This project offers opportunities to put RRI in practice, by supporting research groups in the transition process. In our experience, the process is worthwhile, but at the same time difficult and challenging.

It is important to take time at the beginning of the project to make explicit all the assumptions held by each partner and consider how these assumptions influence project planning and execution. These assumptions and concepts should be revisited periodically in a structured setting within

the consortium to ensure that the partners share a common language and vision when it comes to the activities and goals of the project. Systems thinking approaches can provide a valuable instrument when revisiting assumptions, goals and partners' perspectives.

Partners in the project evidently came from different backgrounds. Also, roles within the project differed. We wanted to set up activities on the platform linked to cohort studies, but at the same time, we wanted to do so in a more responsive and co-creative manner. Ideally, main staff of key Work Packages should be recruited and primed to start at the project outset to allow the methodology to be co-created and tested in the context of the platform together with key project partners.

A central project assumption was that the methodological development would be conducted in close collaboration with an active community on the platform. But two of our key assumptions regarding the platform itself did not work out as we envisaged:

1. *The provision of the online platform and spreading of this information alone would result in numerous suggestions and follow-up activities (Teams and Tasks).*

In reality, only offline events and targeted outreach activities actually led to suggestions on the platform, and these were often via secondary submission.

2. *An active community would form over time, thus increasingly allowing the crowdsourcing concept to be implemented in practice.*

However, few activities emerged over the months after the platform release, and therefore, considerable investment of time was necessary to mobilise networks and individuals via online and offline outreach activities to build an active online community.

At the institutional level, drastically changing the way research is conducted and designed is a time-consuming process. When planning the project, we budgeted one part-time position per Work Package leader institution, and found this to be insufficient. During implementation, actual productive hours were considerably lower than planned due to challenges in recruitment and unexpected extended sick-leave periods. In practice, project staff had to combine working on this project with many other tasks and responsibilities. Making research responsive means slowing down, taking the time to reflect, and that is not always doable when staff resources are inadequate.

Recommendations for future consortia

- Carefully consider staff requirements when estimating the budget: In our case, one part-time position per Work Package was insufficient to manage internal and project-related tasks in a timely manner, which was amplified by unexpected losses in productive hours.
- Sign the Grant Agreement early to allow timely recruitment of key staff members.
- Ensure that the coordination position is continuously filled and respond early if disruptions in coordination are expected.
- Establish and document project processes at the outset, for instance, how deliverables will be reviewed and how project partners can or should contribute to other partner's deliverables or activities. A project manual is a possible approach and can further include the roles and responsibilities of each partner/position.
- Co-create a joint vision amongst partners early on during the project and revisit this process repeatedly to ensure joint understanding.
- Nurture positive partner relations and negotiate early in the process if discrepancies occur.
- Take into account that mobilisation may take considerable efforts and time.
- Team up with other projects dedicated to changing the practice of research and exchange experiences and solutions.
- Communicate any challenges to the designated EU Project Officer early to document reasons and expected delays and seek solutions.
- Do not get disheartened if not everything works out as planned. It is a mutual learning process.