



## **Join Us to Optimize Health Through Cohort Research**

**Meeting Report - RRI Panel Meeting (16<sup>th</sup> June 2021)**

Version 1.0

<b>Project Name</b>	Join Us to Optimize Health Through Cohort Research (JoinUs4Health)
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<b>Project Type</b>	Coordination and Support Action
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<b>Project Website</b>	<a href="https://joinus4health.eu/">https://joinus4health.eu/</a>
<b>Project Coordinator</b>	Birgit Schauer (UMG)
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## Executive Summary

This document reports on the first RRI panel meeting for the project JoinUs4Health, held online on the 16th of June 2021. Included as appendix are the PowerPoint presentations used during the meeting.

## History of Changes

Revision History			
Version	Date	Created/Modified by	Comments
0.0	20/06/2021	Ana Barbosa Mendes (EUR)	First draft of the minutes
1.0	07/07/2021	Ana Barbosa Mendes (EUR)	Revised to incorporate more specific points based on meeting transcript

## Meeting Minutes

### **RRI Advisory Panel – First meeting (M6)**

16th of June 2021

Online

#### Attendees

##### **Project consortium**

- 1) Birgit Schauer (BS) – University Medicine Greifswald
- 2) Hub Zwart (HZ) – University Erasmus Rotterdam
- 3) Ana Barbosa Mendes (ABM) – University Erasmus Rotterdam

##### **RRI Advisory Panel**

All five RRI advisory panel members

#### Welcome and Project Introduction.

HZ welcomed the panel and consortium members for the first RRI advisory panel meeting. Following a round of introductions where each attendee introduced themselves, BS presented the project (please see PowerPoint presentation for details).

Main messages:

- Project aims to combine Responsible Research and Innovation and Crowdsourcing as converging approaches to promote citizen engagement in cohort research.
- In this project, we will build a platform to encourage crowd-level and team-level interactions to tackle challenges in health, where anyone can act as crowdsourcer and propose ideas to be investigated.

#### Crowdsourcing and RRI

HZ presented the philosophical and conceptual basis for combining Crowdsourcing and RRI in the JoinUs4Health project (please see PowerPoint Presentation for details).

Main messages:

- RRI was introduced as a response to the increasing power that science and technology have gained in society. It is a holistic approach that promotes iterative and interactive learning, including societal actors in the knowledge production process.
- Currently in the third phase of RRI, where the focus is on implementation rather than conceptual discussion.

- Crowdsourcing is a way to harness the collective intelligence of online communities, by focusing on concepts such as mutual learning, co-creation and participatory methods.

Related discussions and comments:

ZD: We need tools for doing RRI and embedding RRI as well as to mobilize local communities and citizens

### Role of the panel and project discussion

#### **General discussion – main points:**

- The panel might need a common definition of RRI to guide their work, or they need to understand on how to navigate the different definitions held by the members. However, this project is situated in the pragmatic stage of RRI, focusing on RRI implementation and thus its execution might not depend on a common definition of RRI.
- Since the project focuses on developing a digital platform, it might exclude people who have issues with digital literacy, even though the platform will be designed to be as user-friendly as possible.
- Translation of science to society is crucial for the success of the project, and the project will engage both science communication experts as well as citizens themselves to make that translation. Scientists often do not have the necessary skillset to engage in this translation.
- While scientists will be able to use the JoinUs4Health platform to outsource scientific tasks to citizens, focusing on tasks where scientific expertise is required, the platform's focus is mutual learning between researchers and citizens and scientists.

#### **Structured discussion – reflection questions and main discussion points:**

- 1) We notice that there are different expectations among the consortium partners in terms of how and to what extent citizen engagement should be implemented into the cohort projects. How can we navigate those differences while also staying true to the project's main goals?
  - It is important to understand the sources of hesitation, and the discussion between partners about this topic needs to be an ongoing process. All parties need to be open to revising their own convictions during the process.
    - i. Hesitancy stemming from fear of taking risks can be addressed by conducting smaller pilot studies.
    - ii. If there is hesitancy that is rooted on the potential effect of differences in democratic traditions between member states in engagement, evidence is available that these differences are not important. People are mostly eager to get involved in decision-making, but the way these discussions are framed need to be adapted to local context.
  - Cohort partners might be more comfortable focusing on specific types of stakeholders initially. They can also take advantage of individual contexts in the

study, since using participatory methods means reconciling with unpredictability in research and embedding that uncertainty into the methodology used.

- 2) Should we partner with a commercial organisations that offer platforms that are similar to what we want to create?
- We have some time and budget constraints that could restrict the functionalities that we can implement, so a partnership could expand what we could offer in less time. Therefore, we explored potential partnership options with a commercial company. Discussed were different options of partnership, ranging from engagement as advisory partner to a completely commercial partnership. Unfortunately, there is little option for us to buy access to the platforms, which does not satisfy our project requirements. This commercial option would mean we would lose control over our platform.
  - It is important to consider the sustainability of the platform when entering commercial partnerships. A commercial solution is something very difficult to customise to the needs of the consortium and the cohort studies. The cohort partners would need to be involved in this decision to ensure sustainability.

### Planning for future meetings

#### **Main discussion points:**

- It would be helpful to have a view of concrete scientific information that are expected to come out of the project. One of the expected outputs would be to demonstrate that citizen engagement in cohort studies increases response rates in these studies.
- Creating an online channel for informal interaction in-between meetings could allow for more comprehensive contributions from the panel.

### Discussion regarding the concept

#### **Main discussion points:**

- Anyone can become a facilitator in the platform. Any team can apply for aggregated cohort results (e.g. histograms, frequency tables for a given set of variables with or without stratification criteria). But once a team applies for individual level cohort data, a scientist must get involved in the project. Institutional incentives are encouraged for those scientists to engage in the platform.
- One of the aims of the project is to capacitate and encourage citizens to take on tasks in scientific research that are currently reserved for scientists. This would make citizen engagement less cumbersome as scientists could only focus on input requiring specific scientific expertise.
- Contributions in the platform are completely voluntary, therefore finding ways to incentivise participation is crucial. Students could be encouraged to facilitate teams as

part of their theses, for example. In-person presentations of the platform to potential contributors might also encourage people to engage.

- Participants will be able to suggest topic for future research agendas, but there is no guarantee that these will be taken up. However, we expect that the suggestions will be taken forward by the platform participants when enough people show interest in them. Suggestions not taken up by teams are still collated and accessible in the long-term. If for example any scientist wants to do research on cardiovascular diseases, the database could be screened to find out what suggestions were made; if a suggestion is followed up, the source may need to be acknowledged.

#### Summary of Recommendations:

1. The project should involve science communication experts when planning and implementing the features and content of the platform. (Member 3)
2. The project should network with other European RRI projects (e.g. PARCOS, FIT4RRI, FOSTER) to learn from their experiences. (Member 5)
3. Data privacy issues need to be considered due to the intended use of cohort data by the users of the platform. (Member 5)
4. Mutual learning and internal dialogue should be emphasised from the beginning of the project and should be encouraged throughout the project. (Member 2)
5. Pilot studies can be conducted to explore feasibility of specific approaches and understand how strengths and particularities of each cohort partner can be used to the project's advantage. (Member 2)
6. The approaches that each cohort partner adopt can be flexible and adapt to each partner's needs and strengths, even focusing on specific stakeholder if necessary. (Member 5)
7. The timeline of the project needs to be considered. The project should be in prototyping phase at this stage. (Member 5)
8. An option to attract users to the platform is engaging people who already have some incentive to participate in the platform (e.g. students working on their thesis) or people that have ample time and are looking for activities to fill that time (e.g. retired people). (Member 2)
9. In-person information sessions might help with engaging people to become users and ambassadors for the platform. (Member 3)
10. Response time after user contributions needs to be short, and people engaging in the platform need to be sure their contribution will be heard and responded to. (Member 3)
11. A comparative assessment of cultural differences between the countries involved in the project regarding participation and the way people build expectations and confidence relating to their participation in the platform could be useful. (Member 1)