

Join Us to Optimize Health Through Cohort Research

Meeting Report – 3rd RRI Panel Meeting (11th September 2023)

Version 1.0

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 Coordinator	Birgit Schauer (UMG)
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Version	1.0 – First Draft
Author	Ana Barbosa Mendes (EUR)
Contributors	Hub Zwart (EUR), Birgit Schauer (UMG)
Approved by	

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Executive Summary

This document reports on the third RRI panel meeting for the project JoinUs4Health, held online on the 11 September 2023. Included as appendices are the PowerPoint presentations used during the meeting.

History of Changes

		Revision History	
Version	Date	Created/Modified by	Comments
0.0	20/09/2023	Ana Barbosa Mendes (EUR)	First draft of the minutes
1.0	25/09/2023	Birgit Schauer (UMG), Hub Zwart (EUR), Ana Barbosa Mendes (EUR)	Final draft, ready to be sent to panel members

Meeting Minutes

RRI Advisory Panel – Third meeting11 September 2023

Format: Online (Zoom)

Attendees

Project consortium

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

RRI Advisory Panel

- 1) Enric Bas (EB) University of Alicante, Spain
- 2) Zoya Damianova (ZD) Applied Research and Communications Fund, Romania
- 3) Laurens Landeweerd (LL) Radboud University, the Netherlands
- 4) Simon Ruegg (SR) University of Zurich, Switzerland
- 5) Christiane Grill (CG) Ludwig Boltzmann Gesellschaft, Austria

Welcome and Project Introduction

HZ welcomed the panel and consortium members for the third RRI advisory panel meeting. BS presented an update on the project activities (please see PowerPoint presentation for details).

General Discussion

We opened the floor for general questions and comments from the panel members regarding the project updates. Our dialogue covered the following topics:

- The role of expertise in the project: Expertise can sometimes be put on a pedestal in participatory approaches within RRI and Open Science. At the same time, we need to consider in these participatory approaches, participants might need a specific type of expertise to participate, and they might not have such expertise. In our project, we want to promote epistemic inclusion and value different types of knowledge, including technical and scientific, but also practical and experiential knowledge. Yet, the discussion about what constitutes expertise and how we promote that mutual learning and epistemic inclusion is still ongoing (and we contribute to this, for instance via a paper submitted to the Journal of Responsible Innovation).
- In-person events and their role within the project: We organized offline events in Poland because the Bialystok PLUS cohort only started in 2019 and is thus less well known in the region than the German (SHIP) and Dutch (Rotterdam Study) partner

cohorts. Furthermore, we believed that scientific literacy might be lower in eastern Poland than in the other regions, which are represented in the project, and we thought that would be a barrier for engagement that could be overcome through organizing in-person events. We noticed a better engagement with our platform in Poland, so it would have been useful to organize these events also in the other two regions.

- Lack of engagement in the platform: We had issues with engaging people and attracting users to the platform. We received feedback that our communication was not clear, our aims were too broad, and our platform was not as user-friendly as users would have liked. This is an issue that affects many projects that employ participatory methods.
- **Documenting and evaluating the project might affect its progress:** Given the need for monitoring the project, we as researchers might choose specific methods that would allow for such evaluation, but that this might not be the most suitable method for the project's aims.
- Selecting whom to engage for specific topics: Some topics that are introduced in the platform, whether they are initiated by the cohort institutions or general users, are more relevant for certain stakeholder groups than others. Reflection is necessary on who to target for each topic, with a focus on engaging local communities in the regions that are represented in the project.

Discussing Deliverables 2.2 and 2.3

We provided the panel members with a copy of Deliverables 2.2 and 2.3, which describe our efforts in methodological development and our reflections on institutional changes required for implementation of RRI, respectively. We then invited the panel members to comment on the deliverable and its contents. The panel members provided the following remarks:

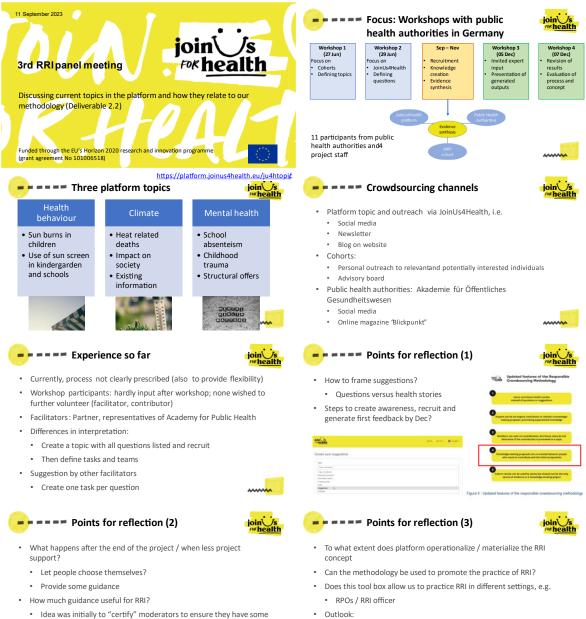
- Knowledge integration takes time and resources: Whether one is aiming to integrate knowledge in an interdisciplinary or transdisciplinary way, that integration requires time and resources to put all stakeholders in dialogue and sustain that dialogue long enough to achieve some sort of knowledge integration. This is a need that should not be underestimated, and to which institutions and funding organizations need to be sensitized. The reflections produced in JoinUs4Health could be useful in highlighting this need.
- The engagement process is already a valuable outcome: Participatory processes are an increasingly valued way for organizations to connect with users or citizens by being more responsive to their needs and concerns. Yet, it is still seen by some organizations as a means to an end. We discussed that since stakeholder engagement is a resourceand time-intensive process, it should be seen as an outcome in itself. Bringing people into productive dialogue is already a noteworthy achievement, and any other outcomes that might emerge as a result of that dialogue are welcome but should not be expected from the outset.
- **Sustainability of the platform:** Without the involvement of professional moderators or some sort of institutionalized support, most crowdsourcing platforms end up in

disuse after the project is done. One way to ensure that this does not happen with the JoinUs4Health platform could be to collaborate with other projects and offer them the platform as a site to support their activities and repurpose the platform to suit their needs. These projects might also be able to help with further engagement, for example by connecting our project with potential experienced moderators.

- Institutions are not designed to enable participatory processes: A project such as JoinUs4Health requires a rethinking of responsibility in the health system as well as the research system. Currently, institutions are not designed to support and reward participation in activities such as the ones that JoinUs4Health aims to support. Therefore, 3-year projects such as ours aim to contribute to an "institutional overhaul" as an important objective of RRI, enabling a shift from research as a competitive enterprise towards research that is responsive to society.
- Doing research that is responsive and relevant to society requires revisiting the role of science: RRI requires constant revisiting of what research looks like, and what should count as a successful process. It requires shifting away from the idea of innovation as a competitive process to a process that is first and foremost meaningful, while also recognizing that determining what is meaningful is challenging.

Appendix 1 – PowerPoint Presentations





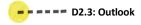
- Idea was initially to "certify" moderators to ensure they have some background
- Our expectation was that facilitators will turn into moderators?
- Who will be moderator

- Possible combination with other tools (e.g. radio show)?Apply for funding of innovation community
- Become part of COST Action on Systems thinking





- Since a new consortium assembles partners from various backgrounds, it is unlikely that there will be acommon understanding of the scope and overall goal of an RRI project, shared by all from the very outset.
- Tensions may emerge for instance between participatory research as a mutual learning endeavour and the deficit model in public engagement.
- It is important totake 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.





- Most participants face time pressures. Academia is a competitive environment, focussed on quantifiable results. RRI requires us talow down.
- RRI is neither a tool nor a method. RRI requiredrastic changes in the way in which research is being conducted.
- A tendency emerged to reduce RRI to a limited set of uantifiable indicators Although indicatorsmay be meaningful for impact assess RRI should not be reduced to mere compliance. RRI is a basic attitude, more than the sum of its parts, emphasising how the various pillars are interrelated. To prevent that RRI becomes a bureaucratic endeavour, bent on quantifying quick wins, the focus should be onchanging the research culture, the institutional ecosystem, making research as such more interactive and responsive.

= = = = = D2.3: RRI



- Before zooming in on the JoinUs4Health endeavour as such, we summarize experiences and results ofprevious Horizon 2020-funded projects
- Making research responsive meansslowing down, taking the time to reflect and learn from one another across projects.
- Ideally, for projects that aim to develop an RRI methodology the design, and preparatory activities of RRI projects should be participatory and constructive as well, by engaging future users in the process.
- At the institutional level, drastically changing the way research is conducted and designed is a timeconsuming process.

= = = = = D2.3: Recommendations



- Co-create platforms with potential users from the beginning of the project
- Take time to create a common language and vision between project partners
 Embed methodology development into a structure of responsibility within institutions involved in the project
- Developing a common language and vision when it comes to the activities and goals of the project, seeing iterative reflections on the assumptions, goals and perspectives as an intrinsic dimension of the work

