



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

**Meeting Report – 3<sup>rd</sup> RRI Panel Meeting (11<sup>th</sup> September 2023)**

**Version 1.0**

<b>Project Name</b>	Join Us to Optimize Health Through Cohort Research (JoinUs4Health)
<b>Project No.</b>	101006518
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<b>Project Website</b>	<a href="https://joinus4health.eu/">https://joinus4health.eu/</a>
<b>Project Coordinator</b>	Birgit Schauer (UMG)
<b>Funded under</b>	Grounding RRI in society with a focus on citizen science (SwafS-23-2020)
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<b>Approved by</b>	

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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 meeting 11 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 resource- and 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

11 September 2023

## Introduction and general project updates

Funded through the EU's Horizon 2020 research and innovation programme (grant agreement No 101006518)

### RRI panel meetings

Meeting	Month	Core topics
1	06/21	<ul style="list-style-type: none"> <li>role of the panel and project discussion</li> <li>how to navigate different expectations among the consortium partners</li> <li>option of partnering up with commercial company</li> </ul>
2	06/22	<ul style="list-style-type: none"> <li>RRI: methodology of interactions</li> <li>RRI: platform</li> <li>RRI: project and research in general</li> </ul>
3	09/23	<ul style="list-style-type: none"> <li>D2.2: Benchmark methodology</li> <li>D2.3: Factors affecting engagement and uptake</li> </ul>

### Overall aim and ambition

Overall aim: JoinUs4Health combines RRI and crowdsourcing as converging approaches

Ambition: To promote inclusive innovation and citizen engagement in cohort research in a co-creative manner, so as to

- make cohort research more sensitive to societal expectations and concerns and
- promote more equal access to science



### Special feature: Cohort access

Cohort project	Country	Cohort	Start	n
Study of Health in Pomerania (SHIP)	Germany	SHIP	1997	4,308
		TREND	2003	4,420
		NEXT	2021	(4,000)
Bialystok Polish Longitudinal University Study (PLUS)	Poland	PLUS	2018	(10,000)
Rotterdam Study (RS)	Netherlands	RS-I	1989	7,983
		RS-II	1999	3,011
		RS-III	2006	3,932
		RS-IV	2016	3,368
<b>Total</b>				<b>27,659</b>

### Platform: Example topics



### D7.4 summary

Experiences platform

- Only offline events and targeted outreach activities actually led to suggestions on the platform
- No active community has formed yet
- Methodology could not be tested in practice yet

Project management

- One part-time position per Work Package insufficient
- Aggravated by recruitment / hiring problems (UMG, MUB, UwB)

### D2.2: Summary

- We devised a methodology to operationalize RRI through crowdsourcing
- Based on our reflections throughout the project, we revised our initial methodology to better encompass the process dimensions of RRI
- Our revised methodology starts from experiential knowledge, where co-creation and knowledge integration is facilitated through collaboration in small teams
- We propose that the platform can stimulate undone science to be conducted

### D2.3: Summary

- RRI, crowdsourcing and cohort research
- Some experiences from previous project
- Recommendations for future projects
- General considerations: the temporal dimension and the institutional environment

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## 3rd RRI panel meeting

Discussing current topics in the platform and how they relate to our methodology (Deliverable 2.2)




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<https://platform.joinus4health.eu/ju4htopi/>

### Three platform topics

Health behaviour	Climate	Mental health
<ul style="list-style-type: none"> <li>Sun burns in children</li> <li>Use of sun screen in kindergarden and schools</li> </ul>	<ul style="list-style-type: none"> <li>Heat related deaths</li> <li>Impact on society</li> <li>Existing information</li> </ul>	<ul style="list-style-type: none"> <li>School absenteeism</li> <li>Childhood trauma</li> <li>Structural offers</li> </ul>

### Experience so far

- Currently, process not clearly prescribed (also to provide flexibility)
- Workshop participants: hardly input after workshop; none wished to further volunteer (facilitator, contributor)
- Facilitators: Partner, representatives of Academy for Public Health
- Differences in interpretation:
  - Create a topic with all questions listed and recruit
  - Then define tasks and teams
- Suggestion by other facilitators
- Create one task per question


### Points for reflection (2)

- What happens after the end of the project / when less project support?
  - Let people choose themselves?
  - Provide some guidance
- How much guidance useful for RRI?
  - 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

### Focus: Workshops with public health authorities in Germany

Workshop 1 (27 Jun)	Workshop 2 (29 Jun)	Sep - Nov	Workshop 3 (05 Dec)	Workshop 4 (07 Dec)
Focus on <ul style="list-style-type: none"> <li>Cohorts</li> <li>Defining topics</li> </ul>	Focus on <ul style="list-style-type: none"> <li>JoinUs4Health</li> <li>Defining questions</li> </ul>	<ul style="list-style-type: none"> <li>Recruitment</li> <li>Knowledge creation</li> <li>Evidence synthesis</li> </ul>	<ul style="list-style-type: none"> <li>Invited expert input</li> <li>Presentation of generated outputs</li> </ul>	<ul style="list-style-type: none"> <li>Revision of results</li> <li>Evaluation of process and concept</li> </ul>

11 participants from public health authorities and 4 project staff



### Crowdsourcing channels

- Platform topic and outreach via JoinUs4Health, i.e.
  - Social media
  - Newsletter
  - Blog on website
- Cohorts:
  - Personal outreach to relevant and potentially interested individuals
  - Advisory board
- Public health authorities: Akademie für Öffentliches Gesundheitswesen
  - Social media
  - Online magazine "Blickpunkt"

### Points for reflection (1)

- How to frame suggestions?
  - Questions versus health stories
- Steps to create awareness, recruit and generate first feedback by Dec?



- Users contribute health stories instead of questions or suggestions
- Stories can be an original contribution or extend a knowledge-making proposal, prioritizing experiential knowledge
- Stories can vote on contributions, but their votes do not determine if the contribution is promoted to a topic
- Knowledge-making proposals are co-created between people who want to conduct and live the proposal
- Expert results can be used by teams but should not be the only source of evidence in a knowledge-making project

Figure 3 - Updated features of the responsible crowdsourcing methodology

### Points for reflection (3)

- To what extent does platform operationalize / materialize the RRI concept
- Can the methodology be used to promote the practice of RRI?
- Does this tool box allow us to practice RRI in different settings, e.g.
  - RPOs / RRI officer
- Outlook:
  - Possible combination with other tools (e.g. radio show)?
  - Apply for funding of innovation community
  - Become part of COST Action on Systems thinking



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### 3rd RRI panel meeting

Discussing barriers and opportunities for RRI implementation  
(Deliverable 2.3)

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### D2.3: RRI



- RRI experienced a pragmatic turn, putting concepts into practice. JoinUs4Health explores whether **crowdsourcing** offers opportunities to enable inclusiveness and societal interaction in **cohort studies**.
- Before zooming in on the JoinUs4Health endeavour as such, we summarize experiences and results of **previous Horizon 2020-funded projects**
- Making research responsive means **slowing 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 co-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 time-consuming process.



### D2.3: Experiences as consortium



- Since a new consortium assembles partners from various backgrounds, it is unlikely that there will be a **common 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 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.



### 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



### D2.3: Outlook



- Most participants face time pressures. Academia is a competitive environment, focussed on **quantifiable results**. RRI requires us to **slow down**.
- RRI is neither a tool nor a method. RRI requires **drastic changes** in the way in which research is being conducted.
- A tendency emerged to reduce RRI to a limited set of **quantifiable indicators**. Although indicators may 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 on **changing the research culture**, the institutional ecosystem, making research as such more interactive and responsive.

