



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

**Meeting Report – 2<sup>nd</sup> RRI Panel Meeting (10<sup>th</sup> June 2022)**

Version 0.0

<b>Project Name</b>	Join Us to Optimize Health Through Cohort Research (JoinUs4Health)
<b>Project No.</b>	101006518
<b>Project Type</b>	Coordination and Support Action
<b>Project Duration</b>	01/01/2021 – 31/12/2023 (36 months)
<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)
<b>Planned Date</b>	30/07/2022
<b>Actual Fulfilment</b>	
<b>Version</b>	1.0 – First Draft
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<b>Approved by</b>	

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## Executive Summary

This document reports on the second RRI panel meeting for the project JoinUs4Health, held online on the 10th of June 2022. Included as appendices are the PowerPoint presentations used during the meeting.

## History of Changes

Revision History			
Version	Date	Created/Modified by	Comments
0.0	15/07/2022	Ana Barbosa Mendes (EUR)	First draft of the minutes
0.1	25/07/2022	Hub Zwart (EUR)	Changes in phrasing in discussion section
0.2	27/07/2022	Birgit Schauer	Comments and changes in phrasing
1.0	09/08/2022	Ana Barbosa Mendes (EUR)	Comments integrated and slides added

## Meeting Minutes

### **RRI Advisory Panel – Second meeting (M18)**

10th of June 2022

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) Ellen-Marie Forsber (EMF) – Oslo Metropolitan University, Norway
- 3) Zoya Damianova (ZD) – Applied Research and Communications Fund, Romania
- 4) Laurens Landeweerd (LL) – Radboud University, the Netherlands
- 5) Simon Ruegg (SR) – University of Zurich, Switzerland
- 6) Christiane Grill (CG) - Ludwig Boltzmann Gesellschaft, Austria

#### Welcome and Project Introduction

HZ welcomed the panel and consortium members for the second RRI advisory panel meeting. Given that we had two new members (SR and CG), every attendee introduced themselves following a brief discussion about the agenda. BS then presented an update on the project activities (please see PowerPoint presentation for details).

#### Discussion

The discussion approached Responsible Research and Innovation (RRI) on three different levels: firstly, RRI as it relates to the interactions that happen within the JoinUs4Health platform; secondly, RRI as it relates to the broader JoinUs4Health methodology and general aspects of the platform; lastly, RRI as it relates to the JoinUs4Health project and the wider scientific landscape. ABM led the discussion by asking previously prepared questions.

##### **RRI at the level of the interactions in the platform**

1. We had initially envisioned a 3 phase workplan, where the team would start with problem probing and systems mapping, followed by project planning and stakeholder involvement and then move on to execution and reflection. Through this

methodology, we would encourage them to engage in systems thinking as it relates to RRI. Therefore, we would like to reflect if we should require or encourage the teams to work in a certain way, and according to RRI principles (specially the RRI process dimensions)?

- In the early phases of the platform, it is advisable to take a gentler approach with the facilitation of the teams to encourage participation and then, if necessary, put stricter methodological guidelines in place.
  - The composition of the team determines what kind of question they choose to investigate as well as how they choose to conduct such investigation. Therefore, constraining team composition rather than the methodologies used by the teams might be more effective in nudging the teams towards a systemic approach.
2. We had initially envisioned that the teams would be self-selected, where volunteers would assign themselves to work on a specific team. In that situation, how can we promote social and epistemic diversity? Should selection criteria for team members be put into place?
- It is important to balance prescription and participation, to avoid the creation of bubbles, where people only work on topics and with people with which they feel comfortable, and to promote innovation, where the teams are not only producing results that were already anticipated.
  - When a team includes both researchers and non-researchers, there needs to be an effort to develop a common language that is not exclusive to non-researchers. Discussions in such teams tend to be dominated by researchers, and the (experiential or otherwise) knowledge that non-researchers bring to the discussion are often dismissed as not valid. Therefore, facilitation is important to ensure that all perspectives are valued and taken into account, and that communication happens in a way that all team members are genuinely included in the conversation.
  - Communication about roles, responsibilities and expectations should be clear and transparent. Community members should know that their contribution will be taken seriously and there should be transparency about whether and how the results that the team produce will be taken up after the management cycle is over, as well as who will be responsible for using such results.
  - A document that outlines what is expected of community members as well as team members specifically could be useful, which could be included in the already existing [Terms of Use page](#). Such document should contain not only guidelines for communication, in a way that promotes respect among the community, but also how the project and the community views expertise.

## **RRI at the level of the methodology and general aspects of the platform**

1. We asked the panel members to explore the platform before the meeting. We welcome any comments on the platform and its features.
  - It is unclear on the platform what JoinUs4Health is and what its goals and purpose are. It is not clear where people should join and how they can contribute. Such information should be provided in language that is accessible to a broad audience.
  - In the platform, it is not clear what would be the incentives for people to participate. People might be motivated by the possibility of contributing to a common good through the platform but to enable that we need to depart from the assumption that people want to contribute to processes that can shape their communities rather than only focusing on individual gains. However, people will only trust that they are contributing to a common good if they have a clear idea of how their contributions will be used to achieve such common good.
  - Participatory budgeting could be explored in the platform, in a way that the regions in which the cohorts are established provide public funding for specific initiatives within the platform, therefore incentivising participation.

### **RRI at the level of the JoinUs4Health project and the wider scientific landscape**

1. How do you see the past, present, and future of RRI as a concept and how do you situate our project in that trajectory?
  - Paradoxically, while a series of recent EU-funded projects resulted in multiple tools for conducting and evaluating RRI and a considerable number of EU-funded RRI projects are still ongoing, we at the same time notice the trend that RRI is being replaced by Open and Responsible Science. However, that does not mean that we as academics and practitioners need to abandon RRI as a concept. RRI, Open Science, transdisciplinary and other agendas that advocate opening up science share underlying values and methods and we should therefore focus on abiding to those values instead of focusing on the labels.
  - The JoinUs4Health project seems to embrace the process dimensions of RRI so it would be useful to make that explicit. However, making a clear connection with the RRI concept might not be necessary. Rather, it could be useful to just tweak the methodology to fit the process dimensions (inclusion, responsiveness, responsibility, and anticipation) and the values that underlie them, while making the connection to RRI visible depends on the context. On the other hand, engaging with the RRI keys would be less useful, even in a non-explicit way since they are already embedded into policy.

### [Planning for the next project phase](#)

BS presents the plans for the next project phase (M18-M30). These plans include new features of the platform, the possibility of an in-person consortium meeting in October 2022, and the



upcoming deliverables for each work package (more details available in the PowerPoint slides in appendix 1).



#### Final remarks

HZ closes the meeting by highlighting the main aspects of the discussion:

1. How RRI evolved as a concept and how our project is situated in its trajectory.
2. What motivation participation in science, and how that connects to our responsibility as a project to ensure that contributions are taken seriously.

## Appendix 1 – PowerPoint Presentations

 <p>RRI and JoinUs4Health Discussion</p>	 <ol style="list-style-type: none"> <li>1. At the level of the interactions in the platform</li> <li>2. At the level of our methodology and the platform</li> <li>3. At the level of the project and RRI research and discourse in general</li> </ol>
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<p>Should we place any <b>methodological constraints</b> in how the teams work on their projects?</p> <p>How much should we <b>expect teams to abide by RRI principles</b> (using the AIRR process dimensions)?</p>	 <p>At the level of the interactions in the platform</p>	<p>How can we promote <b>social and epistemic diversity</b> in the teams if the members are self-selected?</p>	 <p>At the level of the interactions in the platform</p>
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<p>Any <b>aspects</b> that you want to raise about <b>the platform</b>, after having explored it?</p>	 <p>At the level of our methodology and the platform</p>	<p>We focus on <b>suggestions or questions</b> in the community-level interactions. Do you see opportunities for <b>different contributions</b> by the users in this area?</p>	 <p>At the level of our methodology and the platform</p>
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10 June 2022

# join Us FOR health

## 2nd RRI panel meeting

Project updates and questions

# R+HEALTH

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

### The project and our goals

Title: *Join Us to Optimize Health in Cohort Research*

- Project period: 01/21 – 12/23
- 11 partners from three countries

Overall aim: **Combine**

**Crowd-sourcing** & **Responsible Research and Innovation (RRI)**

... to promote

- inclusive innovation and
- citizen engagement

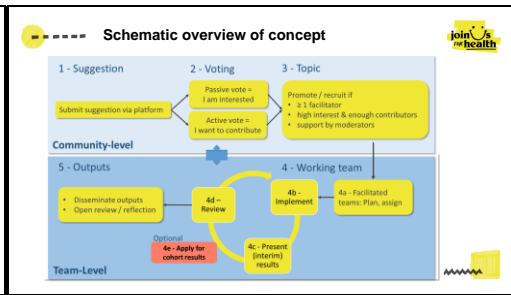
**in cohort research**

Move from deficit to dialogue framework

### The value of the cohorts

Cohort project	Country	Cohort	Start	n	Response (%)
Study of Health in Pomerania (SHIP)	Germany	SHIP	1997	4,308	68.8
		TREND	2003	4,420	50.1
		NEXT	2021	[4,400]	na <sup>a</sup>
Białystok Polish Longitudinal University Study (PLUS)	Poland	PLUS	2018	637	45.4 <sup>b</sup>
Rotterdam Study (RS)	Netherlands	RS-I	1989	7,983	78.1
		RS-II	1999	3,011	67.3
		RS-III	2006	3,932	64.9
		RS-IV	2016	3,368	46
		<b>Total</b>			

<sup>a</sup> Ongoing; started in 2021 (target: 4400 participants until 2026)  
<sup>b</sup> Ongoing; started in 2019



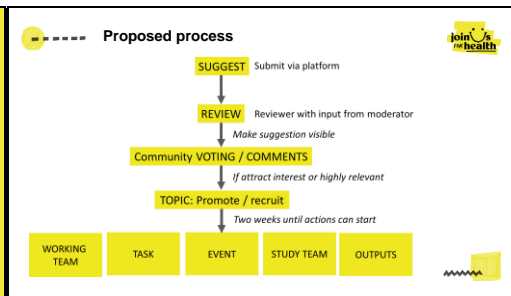
### Postulated key features

- Controlled environment
- Community-based
- Community-driven
- Strategic and operational oversight

### Envisaged outcome

Use voluntary input to generate tangible benefits for (local) societies

Adapted from Rüegg, Hässler, et al. (2018)



### Proposed roles

#### Facilitator

Flexible role (tied to given topic, task or team)  
Anyone can act as facilitator

**Tasks**

- ensure that users adhere to standards and guidelines
- coordinates contributors
- designs plan and ensures its implementation
- reports to the moderator at least monthly

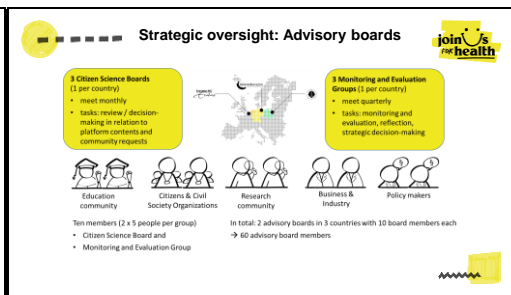
#### Moderator

= Supervisor

Fixed role (tied to user)  
Only selected users (trust, track record, experience, ...)

**Tasks**

- provides high-level strategic oversight
- 1<sup>st</sup> contact in case of questions, complaints
- reviews plan and (interim) outputs
- does not usually join meetings, but can



### Strategic oversight: Featured topics?

- Cohort choose featured topic every 3 months
- Besides, also free topics any time

UMG, MUB, EMC

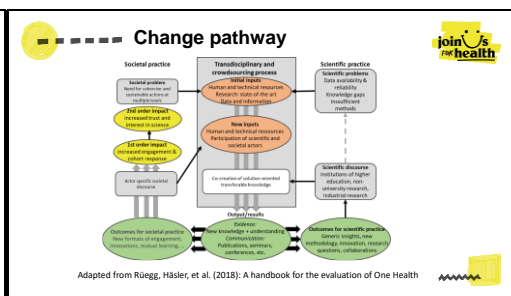
C: 1<sup>st</sup> cycle of management block; 1 cycle = 1 month

Why? Focus community attention, monthly intro of focus topics, evaluation

1 block = 3 cycles = 3 mini-experiment

**Proposed first topics:**

- One Health (UMG, DE),
- sitting / activity behaviour (MUB, PL),
- gender effects (EMC, NL),
- participation in cohort research (UMG)
- ...?



Released on 13/04/22 instead of 12/2021





### Brief tour of the online platform with focus on topics

- Garden for Health
- New European Bauhaus

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



### Example of potential cross-fertilisation


**One Health: Suggestions / topics**

- nature-based therapy
- community garden
- forest gardening
- school lessons in nature


Links?

**Thematic axes**

- reconnecting with nature
- reconnecting with a sense of belonging
- prioritising places and people most in need
- promoting long-term, life-cycle and integrated thinking in the industrial ecosystem



### Dissemination activities



**Scientific conferences**


- Dutch Citizen Science conference : xxx 2021
- DG Epi 2021 : Oral presentation
- Engaging Citizen Science conference in xx, Denmark (25-26 April 2022) : round table discussion
- Epidays, Greifswald, Germany (6-8 April 2022) : oral in-person presentation; note: JoinUs4Health was not the primary focus, but was mentioned as key activity in the abstract and presentation (2 slides)
- Helmholtz Institute for One Health conference, Greifswald, Germany (27-28 April 2022) : oral online presentation
- Open Innovation in Science (OIS) Research Conference 2022 in Austria (11-13 May 2022) : Online demonstration of the platform at session "OIS cases and application"

**Submitted**

- DG Epi 2022: Oral presentation

**Invited talks at working group or consortia meetings**

- CoEvalMR consortium on xx: Oral presentation
- German Working group for citizen science on xx: Oral presentation



10 June 2022




### 2nd RRI panel meeting

### Planning for the project for the 2nd project period

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




### Platform development




**Planned features**


- Page outputs
- Add tools
- Mobile version (was not in original budget)




### Associated tools



Functionality	Tool	Status of implementation
Video calls	Big Blue Button (BBB) system of a German provider (Team21)	Currently, UMG BBB system is available for use Contract to be signed shortly
Online survey	Limesurvey hosted by UMG	Operational, but surveys can only be created by limited circle of UMG staff
Automatic translation	DeepL	Contract to be signed shortly
Joint editing	Wordpress Plugin BuddyPress	Plug-in to be checked
Mind mapping / systems thinking	Wordpress Plugin Mindmap	Plug-in to be checked



### Project phases III and IV



**Phase II: Design**

Platform (WP2), education (WP4), engagement, communication & dissemination (WPs), M&E (WPs)

Academia, Citizens, Education community, Policy, Business

Prerequisite: Institutional changes (WP3)

**Phase I: Conceptualization**


RRI panel and citizen science boards, revision, drivers / barriers / incentives (WP1), M&E (WPs)

**Phase III: Implementation**


**Phase IV: Transfer / transition**

Transfer to others cohorts (consortium) and research institutions, sustainability

Source: Description of Action (2020)




### Planned engagement




Societal group	Sub-group	SHIP			Bialystok PLUS			Rotterdam Study		
		Y1	Y2	Y3	Y1	Y2	Y3	Y1	Y2	Y3
Researchers	Cohort associated	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Other	-	✓	✓	-	✓	✓	-	✓	✓
Citizens	Cohort participants	✓	✓	✓	✓	✓	✓	✓	✓	✓
	General public	-	-	✓	✓	✓	✓	✓	✓	✓
Education community	University students	-	-	✓	-	✓	✓	-	✓	✓
	University of third age	-	-	-	-	✓	✓	-	✓	✓
Policy	Pupils	-	-	✓	-	✓	✓	-	✓	✓
		✓	✓	✓	(✓)	(✓)	✓	(✓)	(✓)	✓
Business		(✓)	(✓)	✓	(✓)	(✓)	✓	(✓)	(✓)	✓
NGOs		-	-	✓	✓	✓	✓	✓	✓	✓

Source: Description of Action (2020)



### Upcoming deadlines and events



- 24/06/22: Evaluation workshop
- 06/22: D6.2 Policy brief
- 08/22: Midterm review (reporting period 03/21-06/22)
- 09/22: Consortium meeting (to be decided) possibly as hybrid event
- 11 or 12/22:
  - D3.2 Report on technical implementation of the platform
  - D4.2 Report on the implementation of institutional changes
  - D5.3 Reports on educational material to teach RRI across different educational levels
  - D6.5 Standard operating procedure document (SOP) to engage high school students via the platform

