Join Us to Optimize Health Through Cohort Research

Deliverable 7.3 Final monitoring and evaluation (M&E) report

Version 1.0

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Deliverable	Deliverable 7.3 Final monitoring and evaluation (M&E) report
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List of consortium partners

Details on partners can be found on our website (link in table above). Partners are listed in alphabetical order by country with details as follows: "Acronym (if applicable): name (role in project)"

Germany: **APH**: Akademie für Öffentliche Gesundheit in Düsseldorf (contribution: WP6), **UMG**: University Medicine Greifswald (lead: WPs 1, 3 and 7)demi

Poland: **MUB**: Medical University of Białystok (lead: WP4), **Science4People** (contribution: WP3), **SocLab**: Fundacja Soclab - Laboratorium Badań i Działań Społecznych (contribution: WP6), **UwB**: University of Białystok, Social Science Department (lead WP6), **Whitebits** (contribution: WP6)

The Netherlands: **EUR**: Erasmus University of Rotterdam (lead: WP2); **EMC**: Erasmus Medical Centre (lead: WP5), **MDOG**: Mijn Data Onze Gezondheid (contribution: WP5), **NPF**: National Patient Federation (contribution: WP6)

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Abbreviations

AIRR	Anticipation, Inclusion, Reflexivity and Responsiveness (components of the RRI process dimension)
D	Deliverable
EC	European Commission
EU	European Union
FTE	Full-time equivalent
M	Month
M&E	Monitoring and Evaluation
MS	Milestone
RPO	Research Performing Organisation
RRI	Responsible Research and Innovation
SwafS	Science with and for Society
WP	Work Package

Executive summary

Funding programme: Between 01/21 and 12/2023, the project "Join Us to Optimize Health Through Cohort Research" (JoinUs4Health) received funding under the European Union's Horizon 2020 research and innovation programme (grant agreement number 101006518). The related call (SwafS-23) stated that 'consortia are expected to implement institutional changes to promote associations' engagement in science, and that these institutional changes are sustainable beyond the lifetime of the project funding period'.

Background: Three of the eleven partners are medical universities implementing population-based cohort studies in their local study regions in Bialystok, Poland (Bialystok PLUS since 2018; Medical University Bialystok), Rotterdam, The Netherlands (Rotterdam Study since 1989; Erasmus Medical Center) and Mecklenburg-Pomerania, Germany (Study of Health in Pomerania [SHIP] since 1997; University Medicine Greifswald). Together these cohorts have produced in-depth databases for up to three decades. These data are used extensively for scientific research, but benefits are not very tangible to local populations.

Project overview: In JoinUs4Health, we aimed to combine Responsible Research and Innovation (RRI) and crowdsourcing as converging approaches to promote inclusive innovation and citizen engagement in cohort research via the implementation of at least six institutional changes. More reflections on the work done can be found in Deliverable (D) 7.5. We developed on line crowdsourcing platform that allows anybody from the age of 16 to submit suggestions, vote or comment on others' contributions or contribute to topics via tasks or teams. Community building is ongoing through on- and offline activities. EMC focussed on formal and informal education to promote RRI achieving valuable expected (e.g. summer school, Minor programme for bachelor students) and forthcoming outcomes (at an institutional level, e.g. fundamental revision of existing medical curricula, and departmental level, including a new RRI research line).

Methods: As part of monitoring, we applied two questionnaires (feedback on the platform; awareness, use and perception of JoinUs4Health amongst SHIP-NEXT participants). In SHIP, we compared cohort response between an intervention group receiving information on JoinUs4Health (n = 4,212) and a control group (n = 1,503) between 05/2022 and 11/2023. Furthermore, we analysed user statistics for the website and platform. As part of evaluation, we applied the NEOH evaluation framework (Network for Evaluation of One Health) and the MICS impact evaluation tool. We carried out two systems thinking workshop to develop a systems map and develop the Theory of Change.

Structure of this report: The aim of this report is to reflect on the value and lessons learnt of the project as a whole as well as individual activities. After a short introduction, we outline the project assumptions (Section 3) and describe applied methods (Section 0). In Section 5, we present results from monitoring activities. Sections 6 to 8 summarize and reflect on outputs from the NEOH evaluation framework. Section 9 provides a summary per Work Package (WP), whilst Section 10 considers societal, democratic, economic, scientific, and environmental impacts. Subsequently, we connect results with selected MoRRI indicators and Sustainable Development goals in Section 11 and discuss aspects related to sustainability (Section 12). The overall discussion (Section 13) revisits assumptions, interprets results in the light of RRI key and process dimensions and summarizes lessons learnt.

Conclusions: The three-year funding period allowed us to design and develop a crowdsourcing methodology and platform. Efforts to build an active (online) community to support the crowdsourcing concept are ongoing. Thus, the project can be considered to be still in the early implementation phase. Although cohort institutions will continue to promote the concept and platform, funding will need to be sourced to provide additional resources (staff, IT resources, mobilization activities) to be able to promote the concept effectively in the region.

1. Background

The SwafS-23 Call "Grounding RRI in society with a focus on citizen science" requires consortia "to implement institutional changes to promote citizens' and their associations' engagement in science, and possibly through an integrated approach covering some or all five fields" (i.e. *engagement in science; formal, informal and non-formal science education; gender equality in science; Research ethics and integrity; Open access*). The call further states that it is expected that the topic will support a significant number of impactful and sustainable institutional changes in partner organisations, which are sustained beyond the project funding period.

The JoinUs4Health consortium includes 11 partners. One partner acted as RRI mentor (EUR), whilst the three cohort institutions in Germany (University Medicine Greifswald; UMG), Poland (Medical University Bialystok; MUB) and The Netherlands (Erasmus Medical Center; EMC) are our main Research Performing Organisations that will implement instructional changes. Furthermore, another university partner (UwB), three non-governmental organizations (SocLab, MDOG and NPF), two private companies (Whitebits, Science4People), and one partner responsible for training of public health representatives (APH) formed part of the consortium.

In the Grant Agreement, we pledged that each of the three cohort institutions will implement at least six institutional changes. The three cohort institutions are implementing population-based cohort research, where randomly selected individuals who were invited to join medical examinations in approximately five-year intervals. More than 30,000 participants have already joined the three cohorts. This longitudinal design (Figure 1) allows investigating incidence of health and disease and related risk factors, whilst comparisons of cohorts in the same study region allow cross-sectional comparisons over time (Table 1). For further information, we refer to design papers (1–4), two pre-prints illustrating the potential role of the cohorts as part of JoinUs4Health (5,6) and video recordings of the recent "Towards comprehensive population studies II Conference" in Bialystok in 12/2023 (7–9).
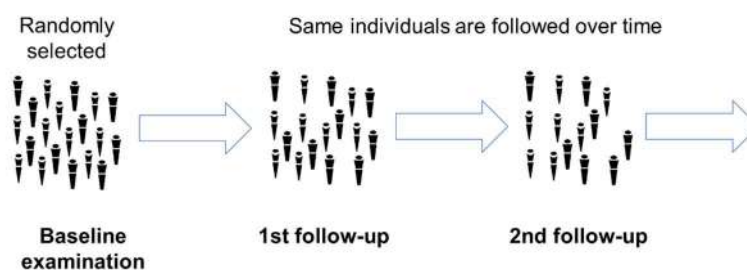
Figure 1. Schematic outline of the longitudinal design of cohort studies.

Table 1. Overview of the year of baseline examination and size of cohorts as well as baseline response in the three cohort institutions participating in JoinUs4Health.

Cohort project	Country	Cohort	Start	n	Response (%)
Study of Health in Pomerania (SHIP)	Germany	START	1997	4,308	68.8
		TREND	2003	4,420	50.1
		NEXT	2021	(4400)	na[a]
Bialystok Polish Longitudinal University Study (PLUS)	Poland	PLUS	2018	(10,000)	na[a]
Rotterdam Study	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	46.0
Total				>30,000	

[a] not applicable as enrolment of participants is ongoing

Table 1 shows a drop in baseline response for the Study of Health in Pomerania (68.8% in START vs 50.1% in TREND) and the Rotterdam Study (from 78.1% in RS-1 to 46.0% in RS-IV). A gradual decrease in cohort response has been observed worldwide. Initially, one of the motivations for the cohorts was to open up cohort research also in the hope that this will make the value of cohort research more tangible to local populations and thus in turn increase cohort response. This would be a clear "business argument" for cohorts to engage with local societies in a more meaningful manner.

Over the three-year funding period, we had the opportunity to implement and test the proposed crowdsourcing concept, gather input and feedback from various sources and reflect on the outcomes and impact of our activities. This Monitoring and Evaluation (M&E) report (D7.3) aims to

- communicate the work done
- reflect on the value and lessons learnt taking into account the initial project assumptions (see Section 0)
- suggest changes (e.g. methodology, institutional aspects, …)
- reflect on good practices, and
- share learnings with the wider community.

The report is complemented by D7.5 (Experiences with citizen sciences) and other project deliverables and is based on exchanges and discussions throughout the project, input from external partners, scientific literature, outputs by other RRI projects and personal discussions.

Important notes:

- This version of the report is largely based on the coordinator's thoughts and will be revised with partners and project contacts early 2024. A revised version may be provided thereafter taking into account proposed revisions.
- Dates are provided in the following format: MM/YY or DD/MM/YY.
- Most project deliverables and other project outputs are available on our project website (https://joinus4health.eu/) and Zenodo (https://zenodo.org/communities/joinus4health).

2. JoinUs4Health project

2.1 Aim, ambition, vision and objectives

Overall aim To combine Responsible Research and Innovation (RRI) and crowdsourcing as converging approaches to promote inclusive innovation and citizen engagement in cohort research.

Ambition To engage 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 to

- make cohort research more sensitive to societal expectations and concerns

- promote equal access to science, especially in the field of health and life sciences.

Vision We want people to live better and healthier lives thanks to trust, understanding, and engagement in science.

2.2 Work packages and objectives

The project includes seven Work Packages (WPs). Work Package (WP) 1 led by UMG outlined initial ethics requirements (D1.1). As part of WP2, EUR (RRI mentoring partner) monitored and advised on activities in the other work packages and contributed to the revision of the proposed crowdsourcing methodology to create a benchmark for future projects (D2.2 and D2.3). Under WP3 (led by UMG), we developed a project website and crowdsourcing platform, which allows scientists, citizens and other societal stakeholders to work together on health-related topics (D3.2). The focus of WP4 (led by MUB) lied on institutional changes and that WP5 (led by EMC) on formal and informal education. WP6 (led by UwB) targeted Communication, Dissemination and Engagement and WP7 (led by UMG) monitoring, evaluation and coordination.

Objectives; in brackets predominantly responsible Work Package (WP[1])

1. ESTABLISH and REVIEW a conceptual framework (WP2)
2. DEVELOP, TEST and APPLY technology to facilitate engaging various actors as part of cohort research (WP3)
3. EXPLORE, IMPLEMENT and MONITOR institutional changes and incorporate RRI into the governance framework of three institutions conducting cohort studies (WP4)
4. ADVANCE RRI and citizen science into the mainstream of public engagement, science communication and education (WP5)
5. PROMOTE engagement and COMMUNICATE and DISSEMINATE outputs via traditional and innovative mean (WP6)

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[1] Work package numbers do not align with the objectives since Work Package 1 was added prior to signing the Grant Agreement.

2.3 Applied crowdsourcing methodology

Details on the crowdsourcing methodology and proposed revisions have been described in previous deliverables (D2.1, D2.2, D3.1). Anybody from the age of 16 can submit "*Suggestions*" (Step 1 in Figure *2*), vote on others' contributions (Step 2) or promote a "*Topic*" as "*Facilitator*" to recruit "*Contributors*" (Step 3). Such activities (submissions, screening, voting, indicating willingness to contribute) are termed "*Community-Level Interactions*" as at that stage no direct exchange takes place between community members (no forum dialogue). Contributors or platform "*Moderators*" can provide relevant background materials (e.g. available research, further information), revise and summarize comments by community members.

If enough contributors volunteer to create a Team, Team members may interact directly ("Team-Level Interactions"[2]) (Step 4). The volunteering Facilitator is responsible for coordinating the team and ensuring reporting of plans, progress, and outputs. A Moderator who should have prior experience with RRI provides a mentoring role (Figure 3). Outputs created by the Team are disseminated via the platform to inform (publicly accessible) promote cross-fertilisation (10) between Topics and Teams.

Teams may apply various approaches to their projects as long it is a health-related topic, rules of conduct are followed and plans / activities are aligned with RRI process dimensions. For instance, at an exploratory stage, focus group discussions or Delphi questionnaire methodology can be used to explore key points related to the question of interest and develop a research proposal specifying tasks and roles. Tasks can subsequently be addressed via direct exchanges (virtual meetings, discussions with stakeholders, review etc) ideally breaking down larger tasks into smaller activities so to offer a circumscribed time of commitment (6). Such Team-Level Interactions match the crowdsourcing types "Broadcast Search" and "Open Collaboration" (11). Teams may require information to be reviewed or gathered. Tasks like this can be outsourced to the community if the Team itself does not include sufficient volunteers or expertise, which resembles "Microtasking" (11).

Most importantly, Teams have the option to apply for cohort results tailored to their topic of interest, if cohorts have suitable data (Step 4a in Figure *2*). We considered the option to a) directly interact with cohort representatives (Moderator and/or outreach within cohort institutions) and b) apply for cohort results as the main selling point of the project and incentive for people to engage.
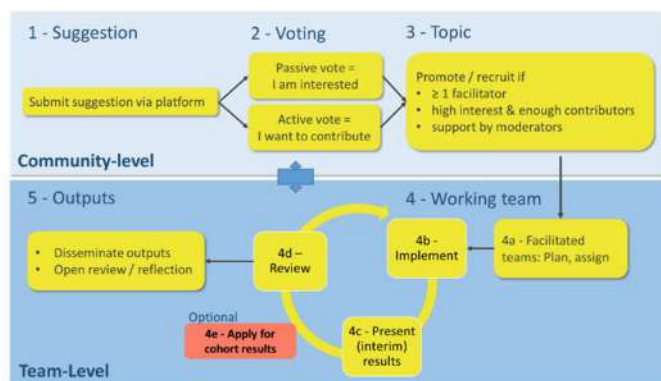
Figure 2. Core steps of the JoinUs4Health Platform to facilitate responsible crowdsourcing.

Figure 3. Extract from a standard slide used for JoinUs4Health presentations.

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[2] Initially the terms "low-level" and "high-level" interactions were used (see D2.1 and D3.1), which were later referred to as community- and team-level interactions, respectively.

2.4 Expected outcomes

During the baseline evaluation, partners were invited to a systems thinking workshop in 06/21 led by Simon Rüegg, who is a senior scientist at the University with interest is the application of the theory of complex adaptive systems to medicine. Based on the workshop, we documented expected outcomes in our Monitoring and Evaluation framework (D7.1):

1. Awareness raising (of cohort research in the region):
    a. due to the different periods of implementation, local societies in the three cohort regions will have a different level of awareness of the cohort studies in their region
    b. but even if awareness exists, currently little is known about details of activities and outputs from the cohort studies

2. Networking:
    a. the platform has the potential to serve as a connector between existing bubbles between and within RRI groups
    b. the platform offers opportunity to connect people from different backgrounds in a secure and controlled environment, which is set up to foster RRI approaches and generate tangible benefits for local societies
    c. the cohorts can contribute their networks they are embedded in as well as their reputation when approaching external networks to mobilise specific stakeholder groups or networks

3. Collation: the collation of suggestions provides a long-term accessible knowledge-base

4. Democratization, by allowing submission of own suggestions, voting on suggestions of others and contributing to activities whilst having a choice between topics, time commitments and types of activities

5. Empowerment, by providing access to structures, processes and outputs developed as part of JoinUs4Health as well as aggregated results or even individual-level data of cohort studies

6. Knowledge generation and innovation: targeted linkages between Community- and Team-Level interactions have the potential to result in cross-fertilization and innovation (10)

7. Generation of tacit knowledge: the advantage of **combining input** from society and science is the generation of tacit knowledge. "An engineer has to check the geological context of where to build the bridge." (Simon Rüegg, 16/09/21)

8. Learning: The concept
    a. offers a range of learning opportunities for citizens, scientists and other societal groups
    b. enables mutual learning and cross-fertilisation between different Teams working on the same or similar topics
    c. allows for more targeted dissemination of information that matters to people.

2.5 Responsible Research and Innovation (RRI)

The RRI concept was included as a cross-cutting issue in Horizon 2020 (H2020), the European Commission's 8th framework program for funding research and innovation. The concept was further elaborated in the 2014 'Rome declaration on RRI' with the intent to stimulate responsibility for better aligning research and innovation with societal values and needs in the European Research Area (ERA).

The European Commission uses the term RRI as a process for "better aligning research and innovation with the values, needs and expectations of society" (12). RRI activities were promoted under the funding programmes 'Science and Society' (FP6), 'Science in Society' (FP7) and 'Science with and for Society' (Horizon 2020). The promoted key pillars of RRI (RRI key dimensions; short **RRI keys**) focus on the operationalization of RRI:

- gender
- ethics
- open science
- public engagement
- science education
- governance

In D2.2 we specified the RRI definition we chose for JoinUs4Health as "taking care of the future through collective stewardship of science and innovation in the present" [(12), p. 1570]. Four **RRI process dimensions** were defined (Anticipation, Inclusion, Reflexivity, and Responsiveness), which is referred to as AIRR framework. These process dimensions set out conditions for research and innovation processes to be responsible (source: https://rri-tools.eu/; access date: 29/11/ 21):

- *Anticipation* / anticipative & reflective: envision impacts and reflect on the underlying assumptions, values, and purposes to better understand how RRI shapes the future. This yields to valuable insights and increase our capacity to act on what we know

- *Inclusion* / diverse & inclusive: involve early a wide range of actors and publics in RRI practice, deliberation, and decision-making to yield more useful and higher quality knowledge. This strengths democracy and broadens sources of expertise, disciplines and perspectives

- *Reflexivity* / open & transparent: communicate in a balanced, meaningful way methods, results, conclusions, and implications to enable public scrutiny and dialogue. This benefits the visibility and understanding of RRI

- *Responsiveness* / responsive & adaptive to change: be able to modify modes of thought and behaviour, overarching organizational structures, in response to changing circumstances, knowledge, and perspectives. This aligns action with the needs expressed by stakeholders and publics

The emergence of these two interpretations of RRI (RRI keys versus RRI process dimensions) is regarded as complementary by some and as less compatible by others. In D2.2, we argue that the RRI process dimensions are more suitable to the JoinUs4Health concept in general. However, we included the RRI keys as part of the evaluation (e.g. as part of Element 3 of the NEOH framework in Section 8 and when reflecting on MoRRI indicators in Section 11.1).

Assumptions on RRI

Extract from D2.2 ("Benchmark methodology on implementing RRI and crowdsourcing for ongoing and future projects"):

- RRI promotes the democratization of knowledge-making, which translates to active participation of the public in science where stakeholders, including researchers, interact to set research agendas, produce knowledge and apply findings in local contexts (13)
- RRI allows for iterative knowledge production, since it is in the interface of science, policy, and practice, allowing for greater potential for societal impact in a shorter time frame when compared to traditional scientific research (14)
- RRI increases the legitimacy of the knowledge making process as well as relevance and external validity of its results compared to conventional research by involving societal actors other than scientists (15)
- fostering a partnership between participants and scientists can increase participation in health research and promote "scientific citizenship" (16)

In reference to JoinUs4Health and the cohort institutions, a partnership should not just be fostered with and among cohort participants as this would introduce bias at follow-up examinations. Instead, the target populations of JoinUs4Health are predominantly the local populations in the cohort regions with the aim to leverage the added benefit of having in-depth and long-term databases available and thus make cohort research more tangible to local populations. The concept is however not exclusive. Contributors from outside the cohort regions are welcome to join.

3. Project assumptions

The initial concept is based on the suggested crowdsourcing approach to bridge the gap between science and public health described in an opinion paper published in 2018 (17). The JoinUs4Health project applied this concept in combination with RRI to cohort research. The following twelve assumptions played a role when we the concept behind the JoinUs4Health proposal was initially designed.

Assumption 1: Willingness to contribute

The "willingness to contribute to a responsible crowdsourcing concept" such as JoinUs4Health can be considered as an individual characteristic with a certain distribution across the population[3]. It might resemble a skewed left distribution (Figure 4), where many people may show no or little willingness to contribute, whilst fewer people are more willing. Those individuals who are 'willing enough' to actually contribute are subsequently referred to as "*Contributors*".
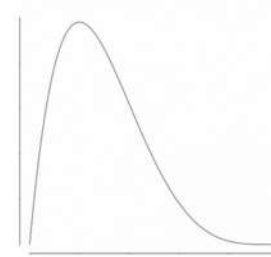
Figure 4. Hypothetical distribution of "willingness to contribute to a responsible crowdsourcing" concept such as JoinUs4Health

Assumption 2: Increased outreach will achieve a critical number of Contributors

Let's now assume a hypothetical cut-off (critical threshold), after which a critical mass of people is reached to identify enough Contributors to sustain meaningful interactions over time via a responsible crowdsourcing initiative. The proportion of Contributors in relation to the overall population might initially still be small. However, we assumed that we would reach enough Contributors to pass this critical threshold if outreach is wide enough to reach a large number of individuals, i.e. by promoting the concept via three cohorts in three countries to different target groups, via various means.

Assumption 3: Need to meet different preferences

Furthermore, we hypothesized that the willingness to contribute depends on the options provided to contribute, as people vary in the time they can commit, their preferred way of contribution (individual-level, e.g. via comments, tasks or likes, versus group-level, e.g. teams) and their preferred type of contribution (e.g. suggestion can be topic of interest, research question, offer).

Assumption 4: Different cohort settings

We expected the awareness of the cohorts in their region to be much higher for SHIP (since 1997) and the Rotterdam Study (since 1989) than for Bialystok PLUS (since 2018). Furthermore, we assumed that in The Netherlands, the willingness to contribute would be higher than in the cohort regions in Germany (Pomerania in the Northeast) and Poland (Bialystok in the East). Since Germany and Poland can be considered similar in their relative lack of prior exposure to citizen science and share similarities (e.g. low population density, high unemployment rate), the Rotterdam Study region was expected to serve as a comparison to the SHIP and Bialystok PLUS study regions.

Assumption 5: Community building

We further assumed that we would succeed in building a community by providing a tool (the platform), collating suggestions via this tool, ensuring responsible conduct of activities (with input

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[3] Whether an individual has the time or the incentive to do that is another question, which is currently ignored.

from citizens and scientists alike) and making outcomes of platform activities publicly accessibly (also to platform visitors; no registration required to view contents). This process in addition to the option to apply for cohort results tailored to the topic of interest was thought to provide sufficient incentive to future Contributors. People who are initially hesitant were expected to increasingly become more willing to contribute in some form, even at a low level (e.g. register, set Likes, make a comment, …).

Assumption 6: Contributors' motivation

A community feeling would increasingly emerge, where people feel that they are part of a project, where meaningful outputs can be created for the local society via combining scientific and societal knowledge and bringing people with different perspectives and (local) insights to the table to seek for integrated health approaches. Hence, our assumption was that Contributors act mainly based on altruistic reasons and due to the opportunity to access cohort resources (results, expertise, etc.).

Assumption 7: User-friendly platform

We expected the platform to be easy to use with a user-friendly interface and a strong appeal, suitable to implement the responsible crowdsourcing methodology to be applied.

Assumption 8: Concept is easy to understand

We thought that we would manage to explain the concept in an easy way and thus be successful in recruiting willing Individuals with relative ease over time.

Assumption 9: Community is in general open to the concept

We expected the local population to show on average more of an interest in the initiative than people from outside the study region as the local population is considered the prime beneficiary of the project. The cohort regions are quite small, so that a high proportion of the target population in SHIP (since 1997) and the Rotterdam Study (since 1989) will either have received an invitation to participate in cohort research themselves or know someone who has been invited.

Assumption 10: Even Non-Contributors are more willing to participate in cohort examinations

We assumed that cohort response in the region would increase not just amongst Contributors, but also amongst non-Contributors. For instance, JoinUs4Health might become a topic of discussion with close individuals (e.g. with family members around the dinner table, with friends at a party), which in turn might increase the likelihood of this individual participating in medical cohort examinations in the future even if no direct Contribution was made towards JoinUs4Health itself.

Assumption 11: Inclusive innovation

Suggestions and contributions as well as outputs generated by Teams would illustrate to both, scientists and citizens alike, the value of opening cohort research to society in various ways such as the emergence of new suggestions, perspectives and generated outputs.

Assumption 12: Willingness of cohorts to sustain institutional changes over time

The observed increase in response and innovation would provide convincing arguments for cohorts to sustain efforts beyond the funding period.

4. Methods

4.1 Monitoring

The monitoring framework provides the means for determining if a programme is on course to achieve its aims. Table 2 shows an overview of instruments used for monitoring activities.

Table 2. Overview of existing instruments applied as part of JoinUs4Health

Instrument	Details
SHIP report including participation of intervention and control group	Reports on SHIP-NEXT baseline response showing numbers of individuals by status of participation, i.e. participated, willing participated (with and without appointment, no reply to date, relocated, deceased, refused, no examination possible in Greifswald.
Questionnaire to obtain feedback on the platform	Target group: Anyone aged 16 years or older accessing the task "Feedback on the JoinUs4Health platform"[4] on the JoinUs4Health platform has access to questionnaire links in four languages (Dutch, English, German, Polish)
Questionnaire on awareness, use and perception of JoinUs4Health	Target group: Participants of the Study of Health in Pomerania who were divided into • an intervention group (⅔ of participants; information on JoinUs4Health and JoinUs4Health stamps) and • a control group (⅓ of participants; no prior information on JoinUs4Health and SHIP stamps) See Appendix IV for details on the questionnaire
Webalizer (from 11/23 also Matomo)	• monitoring of user traffic on the website and platform • analysis of user behaviour

In SHIP, we compared the baseline response for the SHIP-NEXT cohort, which is the third cohort of the SHIP project (Table 1). The NEXT cohort started in mid-2021 with the aim to enrol over 4,000 participants. Selection of SHIP participant is at random using population registries of the federal state of Mecklenburg Pomerania. Details are described elsewhere (18).

From 05/22 to 11/23, individuals who were invited to participate in the SHIP-NEXT cohort were randomly assigned to the JoinUs4Health intervention (2/3) or to a control group (1/3). The intervention group received

- a cover letter explaining the project
- the project flyer
- four JoinUs4Health stamps (control group: SHIP-stamps)

Initially, most of the invitees have not previously heard of JoinUs4Health. Over time, the level of awareness of the project was expected to increase.

Both groups received a short self-completion questionnaire, which participants fill out when they are at the SHIP examination centre to assess reasons for participation, awareness of and level of exposure to the JoinUs4Health project. The questionnaire includes 10 questions:

- reason for participating in SHIP (Question 1)
- awareness (level) of the project (Questions 2-4)
- if project is known: Level of interaction with the project (Questions 5-8)
    - website,
    - platform visit,
    - platform registration,

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[4] https://platform.joinus4health.eu/ju4htask/feedback-to-the-joinus4health-platform/

- o contribution: submission suggestion, contribution to task, engagement in team, participation in event
- impression (Question 9) and expectations (Question 10) of the project

Results are summarized in D7.5.

For monitoring user traffic on the website and platform, we used two tools:

- Webalizer (see https://webalizer.net/; in use since 04/21) allows generating detailed and configurable usage reports in HTML format. The usage reports generated in JoinUs4Health provide information on Files, Pages, Visits, kB Files, kB In and kB Out aggregated by hour, date, referrers and countries.
- Matomo Analytics (see https://matomo.org/; in use since 11/23) is a free libre and open source software, to generate more advanced reports. Matomo is an open source web server log file analysis program distributed under the GNU General Public License.

4.2 Evaluation

Table 3 outlines the activities carried out as part of the baseline, interim and final evaluation.

Table 3. Activities carried out as part of the baseline, interim and final evaluation to support the process and impact evaluation

Evaluation stage	Process evaluation	Impact evaluation
Baseline	Design thinking workshop led by SocLab	• 1st Systems Thinking workshop (--> systems map) • Exploration of NEOH framework
Interim	Interviews with partners (--> narrative interim evaluation report)	• 2nd Systems Thinking workshop (--> revised systems map) • Exploration of MICS impact evaluation tool kit
Final	Exchanges with partners, advisory board members and engaged stakeholder groups	• Based on exchanges • Follow-up meetings with regional partners in 01&02/24

4.2.1 NEOH framework (process and impact evaluation; all stages of the evaluation)

Challenges calling for integrated approaches to health typically deal with complex (sometimes also called wicked) problems. One Health deals with integrated health approaches at the interface of humans, animals, and ecosystems constituting their environment. Birgit Schauer (coordinator; WP7 lead; UMG) is a trained veterinarian who has worked as epidemiologist at the UMG since 2015. She has a strong One Health background, and parallels between One Health and RRI became especially clear when selecting an evaluation framework in relation to the RRI process dimensions (D7.1).

The NEOH framework was developed as part of the EU COST Action (TD 1404) "Network for Evaluation of One Health" (NEOH) to evaluate One Health initiatives and demonstrate the added value arising from knowledge integration (19). The NEOH framework includes four overarching elements:

- **Element 1:** the definition of the initiative and its context (see Section 6),
- **Element 2:** the description of the theory of change with an assessment of expected and unexpected outcomes (see Section 7),
- **Element 3:** the process evaluation of operational and supporting infrastructures (the "OH-ness") (see Section 8), and
- **Element 4:** an assessment of the association(s) between the process evaluation and the outcomes produced (not yet performed).

For Element 3, ready-to-use Microsoft Excel spreadsheets (LINK) are available to assess the "OH-ness" of the initiative. This tool includes 80 questions relating to six aspects combined into

- Organisational aspects: Thinking, Planning, Working,
- Infrastructural aspects: Sharing, Learning, Systemic organisation.

Calculation of scores

The median of the semi-quantitative scores, which can range between 0 and 1, is then calculated for each of these six areas and displayed as a hexagonal spider diagram, where operational aspects (Thinking, Planning and Working) are shown on the top left of the diagonal and infrastructural aspects (Learning, Sharing and Systemic Organization) on the bottom right. The **One Health Index** calculates the area of the hexagon covered in Figure 10. The symmetry over the diagonal of the

spider diagram is numerically represented as the **One Health Ratio**. The framework has been widely promoted and applied in One Health contexts, and various case applications have been documented and (20). There is no recommendation yet on the optimal ranges for One Health Ratio and One Health Index (21).

Adaptations for the use of JoinUs4Health

Figure 5 shows an overview of these elements applied to the JoinUs4Health project (source: D7.1). The mixed methods approach combines a descriptive and qualitative assessment as well as a semi-quantitative scoring for the evaluation of the degree and structural balance of "OH-ness" (summarised in an OH-index and OH-ratio, respectively). Further background description is available in the Info-sheet of the supplementary Excel spreadsheet (21).

In support of this framework, we organized two systems thinking workshops for project partners and invited guests, which were led by Simon Rüegg from the University of Zurich (06/21) and Johanna Dups-Bergmann from the Friedrich Loeffler Institut Greifswald, Riems (03/22). Furthermore, Johanna Dups-Bergmann conducted interviews with all Work Package leaders in the first half of 2022 in preparation for a narrative interim report, which was shared with project partners.
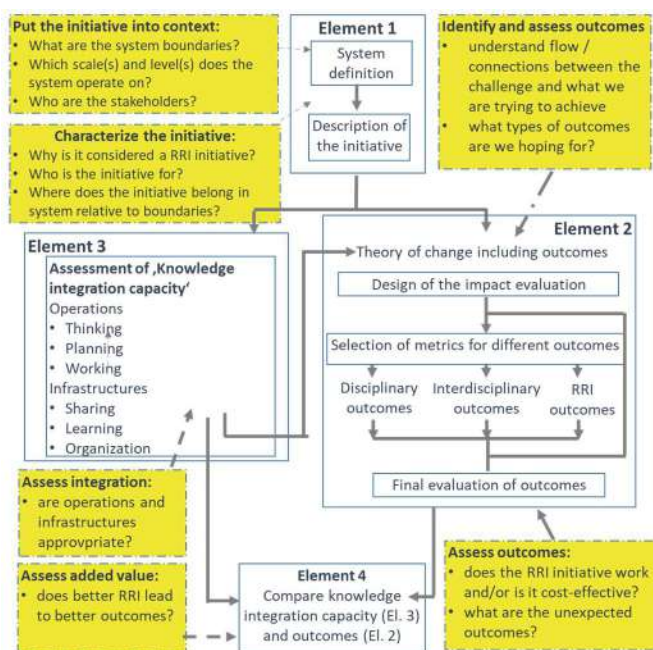
Figure 5. Flow chart of elements to be considered during the JoinUs4Health evaluation (clear boxes) with their purpose and the associated questions to be answered (yellow boxes). Adapted from Rüegg, Nielsen et al. (2018) (21).

4.2.2 MICS tool

In response to a recommendation from the project's midterm review, we also applied the MICS evaluation tool for impact evaluation[5] as part of the final evaluation. The easy-to-use *MICS platform* includes a set of 200 questions with pre-defined answer categories grouped under different impacts. The *MICS guidance* provides details of various impacts of citizen science, on the importance and ways of measuring impacts and on co-designing citizen-science initiatives. Birgit Schauer (UMG) created a project on the MICS platform[6], answered the 200 questions and reflected on activities, exchanges and resulting outputs throughout the project based on the recommendations.

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[5] https://about.mics.tools/
[6] https://mics.tools/projects/joinus4health

5. Monitoring results

5.1 User statistics website and platform

The change in the number of hits on the website and platform showed a similar pattern until 07/23, when platform use increased (Figure 6a). Aggregated user statistics cannot differentiate between hits by project partners (e.g. the IT development team) and platform users, which presents a potential source of error. However, the number of visits of the platform showed a similar pattern to the number of visits, which indicates that the increased platform use compared to the website was a true difference (Figure 6a and b).#

User traffic for the months of 11 and 12/23 has not been analysed yet. But a stark increase occurred by mid-Dec due to the activities in Poland and Germany continuing until mid-December.

Cautionary notes:

- Partners visited the platform throughout the project. We cannot differentiate between platform users, visitors and partner activities (developers, content moderators). Website visits provide a more or less reliable indicator of outreach as partners made few adjustments over time, whilst the platform was still under development and thus visited by consortium partners.
- Furthermore, we cannot determine to what extent the use was due to bot activity.
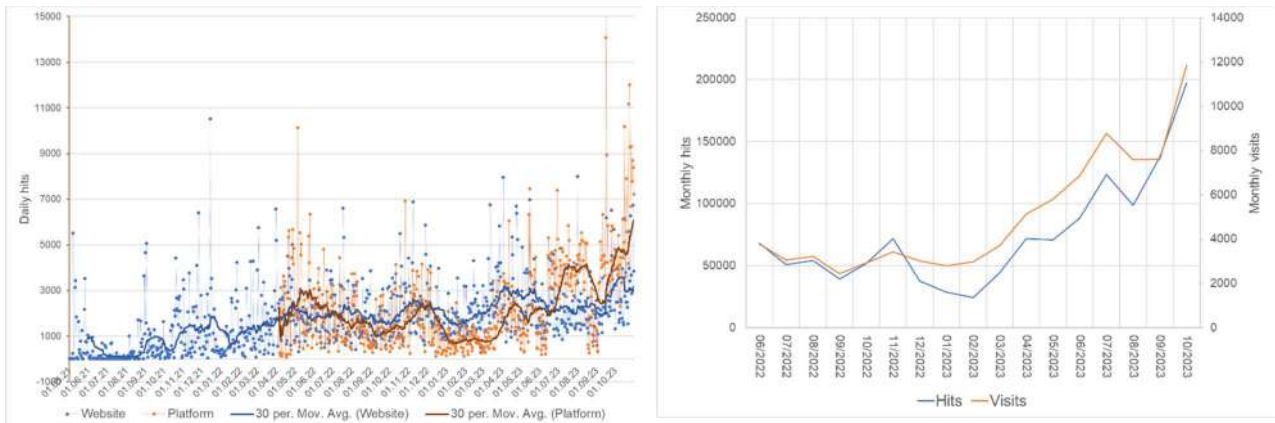
Figure 6. a) Daily hits on the JoinUs4Health website (blue) and platform (orange) with 3ß0-day moving averages and b) monthly hits and visits on the JoinUs4Health platform between 01/10/21 and 31/10/23.

5.2 Cohort response

This section compares the response observed in the intervention and control group based (status: 04/12/23):

The comparison of the two groups either receiving information on JoinUs4Health (JU4H) or not (No JU4H invitation) are shown in Table 4. The percentages of invited individuals who agreed to participate or participated already (☺) was numerically higher in the control group (26.0%) who was no informed about JoinUs4Health than in the intervention group (24.4%), but this difference was insignificant given the overlapping confidence intervals.

Table 4. Percentage and 95% confidence intervals (Conf. Int.) of individuals invited to take part in the Study of Health in Pomerania (SHIP) in Greifswald, Germany, between 05/21 and 11/23 grouped information on and invitation to take part in JoinUs4Health.

	Status	JU4H invitation (n = 4,212)		No JU4H invitation (n = 1,503)	
		Percent	Conf. Int.	Percent	Conf. Int.
☺	Participation confirmed (with or without appointment)	4.5	3.9 - 5.1	5.0	4.1 - 5.9
☺	Participation completed	19.9	18.7 - 21.1	21.0	19.4 - 22.6
☺	No response yet	72.5	71.1 - 73.8	69.9	68.0 - 71.7
☹	Refusal	3.2	2.7 - 3.8	4.2	3.4 - 5.1

JU4H invitation: information on JoinUs4Health was included with invitation letter
No JU4H invitation: no information was included (i.e. standard invitation process)
Individuals who had relocated or deceased were excluded.

6. NEOH Element 1: Context

6.1 Temporal settings

During the project funding period (2021-2023), various societal challenges have arisen or manifested themselves:

- Climate change and increasing loss of biodiversity
- Conflicts between Russia and Ukraine (since 02/22) as well as Israel and Gaza (since 10/23)
- Direct and/ indirect effects of the covid pandemic
- Growing mistrust of science, medicine and public health
- Growing polarisation
- Increasing overall political drift towards the right
- Challenging economic situation with increasing fuel prices and high cost of living, reducing the purchasing power of households
- High uncertainty, particularly related to energy security, weighs on investment (22)

Such challenges have also affected the scientific landscape:

- Due to the economic pressure the funding landscape is changing.
- The higher energy costs and the covid pandemic have drained budgets.
- Staff is being cut down.
- Overall higher uncertainty also in the scientific community.
- Lessons to be learnt from covid

As a result, there is an increasing realization in science and politics that it is crucial to bridge the gap between science and society, especially in present times (polarization, need for transformative changes, uncertainty).

Furthermore, elections took place in two of the three participating Member States:

- Poland [7]:
    - After 8 turbulent years with the conservative Law and Justice party in power,
    - Donald Tusk, who was former Polish prime minister from 2007 to 2014 and acted as president of the European Council from 2014 to 2019, led three opposition parties that vowed to restore democratic standards in Poland together in the 2023 general election
    - The coalition of the three opposition parties won over 54% of the votes in the nation's parliamentary election following a historical voting turnout of 74.4%, the highest in contested elections and the highest since the fall of the Soviet Polish People's Republic
- The Netherlands:
    - The elections had been expected to be held in 2025
    - But snap elections were called after the fourth Rutte cabinet collapsed in 07/23 following disagreements between parties on immigration policy.
    - The polls delivered a turn to the far right [8]

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[7] https://www.euronews.com/2023/10/17/final-results-show-scale-of-pro-eu-opposition-victory-in-poland
[8] https://think.ing.com/snaps/dutch-election-result-brings-risk-of-more-eurosceptic-policies/

6.2 Geographical settings

The total population of the study regions of SHIP, the Rotterdam Study and Bialystok Plus comprises an estimated number of 244, 630 and 300 thousand inhabitants. The study regions of the Rotterdam Study and Bialystok PLUS are larger cities. On the contrary, the SHIP study region covers

- two rural districts with two cities (Greifswald and Stralsund, both with almost 60,000 inhabitants)
- three towns (Grimmen, Anklam and Wolgast, with 10,000 to 12,000 inhabitants each) and
- 99 rural communes with median population densities of 26 inhabitants per km^2 (interquartile range: 17 – 50)

Both the SHIP and Bialystok study regions are border regions (SHIP: Poland; Bialystok: Belarus) and belong to the economically less developed regions in their country. The Bialystok PLUS study describes the health status of the adult population in Bialystok city in East Poland. The SHIP cohort study region is situated in two districts (Pomerania-Rügen and Pomerania-Greifswald excluding the islands and remote rural areas) in Mecklenburg-Pomerania in Northeast Germany (*Figure* 7a).

German   **The Netherlands**   **Poland**
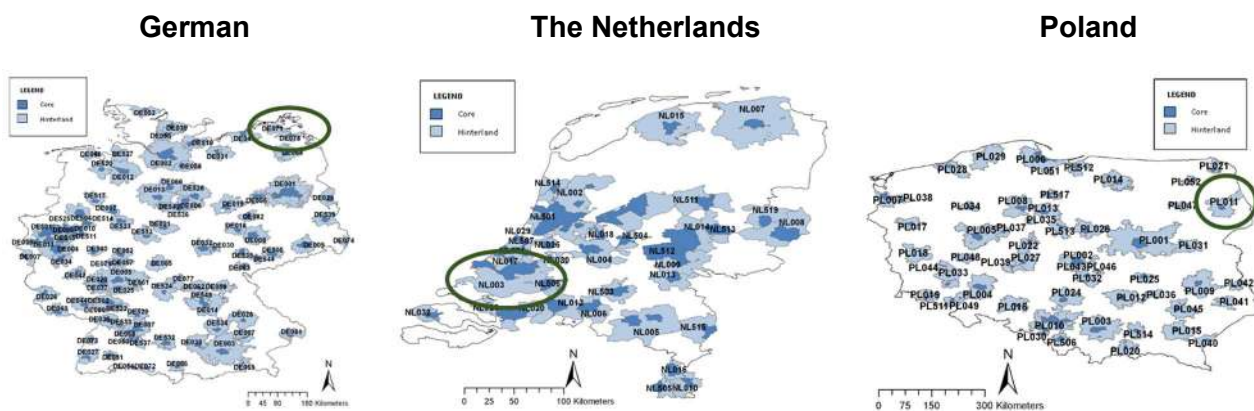
Figure 7. Urban metropolitan areas in Germany, The Netherlands (middle) and Poland (right) with the cohort regions indicated by the green circle
Study of Health in Pomerania: DE071 and DE078; Rotterdam Study: NL003; Białystok PLUS: PL011)

An interesting recent finding is the comparison of Mecklenburg-Pomerania to the national average when it comes to life satisfaction, and in particular in the change in life satisfaction after 2021. Overall, in Germany, life satisfaction decreased during the Corona pandemic from approximately 7.1 to 6.5, but increased thereafter to 6.8 (Figure 8). In contrast, Mecklenburg-Pomerania experienced an earlier drop in life satisfaction, and the decline in life satisfaction continued even after 2021 to an all-time low of 6.2 in 2023.
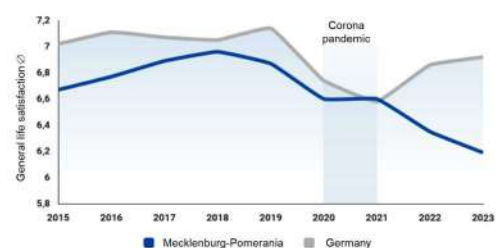
Figure 8. General life satisfaction in Mecklenburg-Pomerania compared to the German average[9]

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[9] https://www.skl-gluecksatlas.de/artikel/gluecksatlas-2023-mecklenburg-vorpommern.html

Table 5 compares OECD metropolitan indicators between the three metropolitan areas of or closest to the study regions in Germany [Rostock(DE)], Poland (Bialystok) and The Netherlands (Rotterdam):

- Population density: Rostock (DE) and Bialystok are amongst the least populated regions in their countries (DE: 119 inhabitants / km^2; PL: 189), both in the
  - core area (DE: 1243; PL: 2864) and
  - hinterland (DE: 63; PL: 62).
- Elderly dependency ratio was lowest in the Rostock (DE) region (98.9) compared to Bialystok (100.2) and Rotterdam (105.1)
  - Note: Greifswald itself (where UMG is situated) is a university city with a relatively high proportion of young people. But the hinterland population has a high proportion of elderly people, which is reflected in the presented statistics
- Growth/shrinking index: Rostock (DE) shrank (98.9), Bialystok remained stable (100.2) and Rotterdam grew (105.1)

Furthermore, both the SHIP and Bialystok regions are historically characterised by high poverty rates. Poverty rate after taxes and transfers (based on Poverty line 60%) (source: OECD.stats Dataset: Regional Well-Being[10]):

- Mecklenburg Pomerania (SHIP): 24,2% (national average: 15.3%)
- East region (Bialystok PLUS): 21.4% (national average: 17.3%)

Table 5. Selected metropolitan indicators OECD.stats Dataset: Metropolitan areas (https://stats.oecd.org/Index.aspx?DataSetCode=CITIES; date accessed: 14/12/23)

	Rostock	Bialystok	Rotterdam
Population density / km^2	119	189	862
… core area	1243	2864	1923
… hinterland	63	62	348
Elderly dependency ratio (65+ over population 15-64)	39.7	27.4	28.7
Growth/shrinking index of the total population (2001=100)	98.9	100.2	105.1

[a] The SHIP study region in Pomerania-Rügen and Pomerania-Greifswald is even more rural than Rostock.

[10] https://stats.oecd.org/Index.aspx?DataSetCode=CITIES#

7. NEOH Element 2: Systems thinking and Theory of Change

In JoinUs4Health, we applied systems thinking to describe the theory of change at two occasions:

- In 06/22: Led by Simon Rüegg; University of Zurich
- In 02/23: Led by Johanna Dups-Bergmann

The resulting discussions and systems maps formed the basis to

- identify key elements and interrelations of the system as part of the design of the evaluation framework (baseline evaluation; workshop in 06/22; output: D7.1)
- gain a better mutual understanding amongst partners regarding the key elements of the project (interim evaluation; workshop in 02/23; output: systems map and interim evaluation report), and
- identify which indicators must be monitored (current final M&E report).

In D7.1 we had outlined the Change Pathway (*Figure 9*) with the following expected 1st and 2nd order impacts:

- 1st order impact
  - innovation: Through cross-fertilization and diversity
  - empowerment of citizens: Through participatory democracy
  - integration of knowledge: Through valuing diverse inputs
  - …
- 2nd order impact
  - Increased trust and interest in science
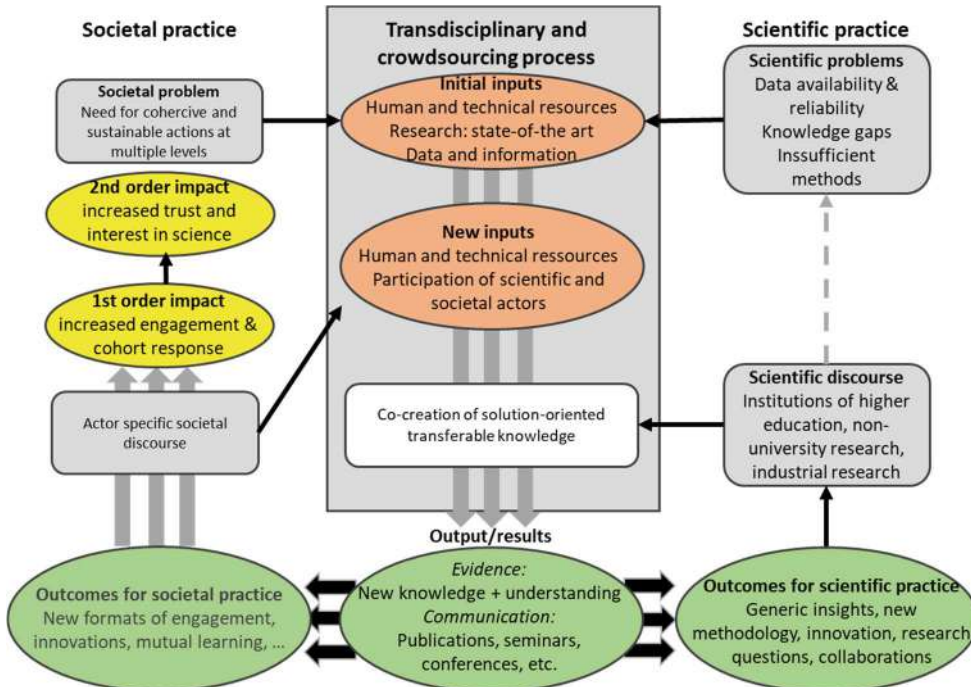
Figure 9. The change pathway for the JoinUs4Health project adapted from Rüegg, Häsler et al. (2018)

8. NEOH Element 3: Process evaluation

Element 3 of the NEOH evaluation tool was used as part of the process evaluation. Section 4.2.1 provides more details on the six aspects Thinking, Planning and Working (organisational) as well as Sharing, Learning and Systemic Organisation (infrastructural). Results are currently solely based on the assessment by the coordinator taking into account the discussions and activities throughout the project to the best knowledge. The assessment will be opened for revision with partners, contributors and network contacts in 01 and 02/24.

Details of each aspect are summarized in Table *6*. A narrative reflection on each of the six assessments is provided in Appendix 3.2.

- Operational aspects: Working achieved the highest score (0.8) followed by Thinking (0.74) and Planning (0.6). Whilst the project represents a comprehensive transdisciplinary, integrated health approach, sustainability and planning considerations could have been strengthened.
- Infrastructural aspects: All the three aspects show some strengths and weaknesses. Information and data sharing was to a large extent impeded by the lack of time and differences in perspectives, which could never be fully overcome. Overall, team collaboration between partners can be considered positive.

The spider diagram in Figure 10 shows the scores of each assessment and illustrates the degree of integration by the proportion of the surface of the hexagon covered (area is expressed via the "OH"-Index: 0.41) and the balance between the operation and the supporting means through its symmetry over the diagonal ("RRI"-Ratio: 1.24). The OH index (degree of integration of operational and infrastructure aspects) was 0.41. The OH ratio (1.24) reflecting an overall balance between operational and infrastructure aspects of the initiative through its symmetry over the diagonal on the spider diagram (Figure 10).

Interpretation of OHI and OHR: There is no benchmark for a OH index or ratio as it is not (yet) clear what level of integration would facilitate the best impact. However, the spider diagram illustrates that JoinUs4Health is thought in a comprehensive manner, which however is not matched by the other aspects of knowledge integration. The management structure of the cohort institutions as learning organisations is largely decentralized. Therefore, the three sites were not truly integrated and the organisation at each site was quite agile, i.e. the knowledge integration was different at different levels of governance). The OHR indicates that there was quite a good match between the intended operations and the provided infrastructure.
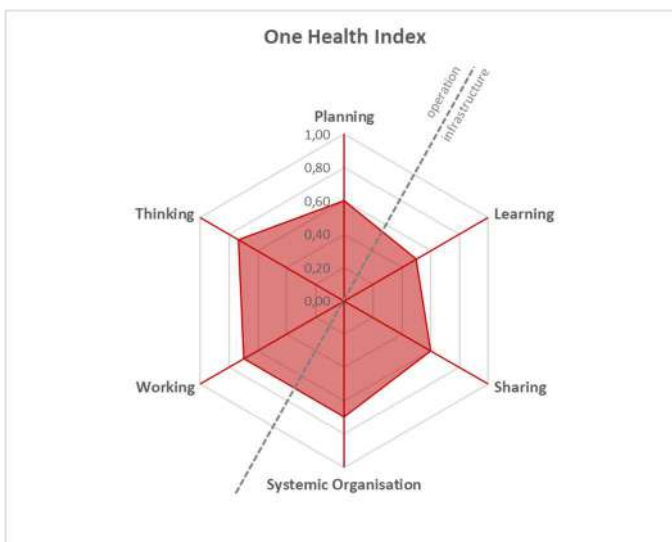
Figure 10. Spider diagram visualising the six assessments, i.e. the operational aspects ('Thinking', 'Planning' and 'Working') on the top left of the diagonal and the infrastructure ('Learning', 'Sharing' and 'Systemic organisation') on the bottom right.

Table 6. Summary of scores resulting from applying the Excel spreadsheet to assess Element 3 of the NEOH evaluation framework[11] for the JoinUs4Health project when assessing Thinking, Planning, Working as well as Sharing, Learning and Systemic Organisation

	Thinking *Degree of thinking in and about the initiative and the system in which it operates (context)*		**Planning** *Match between tasks, resources, and responsibilities*		**Working** *Transdisciplinarity, cross-disciplinarity and leadership enabling an innovative approach*	
Organisational aspects	Overall score	0.74	Overall score	0.6	Overall score	0.8
	Dimension coverage and balance	0.7	Common aims	0.9	Broadness of initiative	0.6
	Initiative to environment match	0.6	Stakeholder and actor engagement	0.5	Collaboration	0.5
	Integrative health approach	1.0	Self-assessment and plan revisions	0.5	Transdisciplinary balance	0.8
	System features and target	0.6	Objective 1	0.6	Cultural and social balance	0.6
	Sustainability and social–ecological considerations	0.5	Objective 2	0.6	Flexibility and adaptation	0.7
	Perspectives and Theory of Change factors	0.6	Objective 3	0.6		
			Objective 4	0.8		
			Objective 5	0.6		
	Sharing *Overall data and information sharing infrastructure*		**Learning** *Learning infrastructure*		**Systemic Organization** *Leadership skills and criteria for effective teamwork*	
Infrastructural aspects	Overall score	0.6	Overall score	0.5	Overall score	0.7
	General information and awareness sharing	0.6	Focus on adaptive and generative individual learning	0.4	Team structures	0.5
	Data and information sharing	0.8	Focus on adaptive and generative team learning	0.5	Social and leadership structures and skills	0.65
	Methods and results sharing	0.6	Focus on adaptive and generative organisational learning	0.4	Competence	0.5
	Institutional memory and resilience to change	0.7	Direct learning environment supportive of adaptive and generative learning	0.7	Focus on innovation	0.8
			General learning environment supportive of adaptive and generative learning	0.5		

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[11] https://neoh.onehealthglobal.net/

9. Evaluation by Work Package

9.1 Work Package 1

9.1.1 Objective

To set out the 'ethics requirements' that the project must comply with.

9.1.2 Actions performed

- Information of the UMG Ethics Committee and consultations upon demand
- Interactions with the UMG Data Protection Officer and if required legal department
- Exchanges with partners on ethical aspects
- Contribution to the TIME4CS webinar "Ethical aspects of Citizen Science: good practices and institutional interventions" on 16/05/23
    - JoinUs4Health was presented as an ETHNA[12] case study
    - In preparation, Birgit Schauer replied to four questions posed by the ETHNA consortium, which are available on Zenodo
    - Question 1: How is research expertise offered? Points mentioned:
    - Question 2: How are the population requests/proposals taken on-board? Points mentioned:
    - Question 3: What is the role of the institutions in the platform offered to engage general public and researchers? Are they part of the interactions or this is done by individual researchers / research teams?
    - Question 4: If institutions do not play a role, do you see a way of partnership stemming from JoinUs4Health interactions, which could apply an "institutional-like" governance system? Or in other words, how are the cohorts in the high-level interactions managed?
    - Question 5: Are there other ethical concerns in low-level interactions beyond GDPR considerations? (mentioned: reciprocity, inclusion)
    - Question 6: Considering the interaction of the case study selected, which tools of those proposed by the ETHNA System could be most relevant?
- Exchanges prior and after the meeting, respectively, with two ETHNA representatives including a RRI officer: Reflection on the potential use of the platform as RRI officer

9.1.3 Relevant project outputs

- D1.1 ("Protection of Personal Data: POPD - H - Requirement No. 1") was submitted on 05/05/21 (9 pages) covering three main parts:
    - Inclusion, identification and recruitment of citizen scientists (inclusion; identification and recruitment of participants)
    - Technical measures for the platform (general measures; personal information to be collected), Organizational measures for the platform (Data Protection Officer; informed consent)
    - Security and Safety measures (Prevent unauthorised access to personal data and data loss incl. control mechanism; processing of previously collected data)

9.1.4 Impacts achieved

- D1.1 as a reference for other Work Packages, in particular WP3

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[12] https://ethnasystem.eu/; ETHNA ("Ethics Governance System for RRI in Higher Education, Funding and Research Centres") is a project also funded from the EU's Horizon 2020 research and innovation Programme (Grant Agreement No 872360; 01/01/20 – 30/06/23)

- Webpage and platform design and management, which comply with specification of D1.1
- Learnings and feedback from the TIME4CS workshop in 05/23
  - assessment of ethical aspects of JoinUs4Health in discussion with the ETHNA and TIME4CS representatives and webinar participants
  - familiarization with the tools of the ETHNA System aimed at building trust between people, administration and organisations, namely:
    - Code of Ethics and Good Practices
    - Ethics Committee on R&I
    - Ethics Line
  - exploration of the application of the JoinUs4Health concept and platform from the perspective of an experienced RRI offer taking into account experiences in Spain

9.1.5 Reflections

- Ethics was initially thought to be covered under WP2 ("Ethics and RRI"), but was separated from WP2 before signing the Grant Agreement. No dedicated staff resources were assigned to WP1 so that UMG covered WP1 through WP7 resources with internal support.
- Given lack of in-depth interactions on the platform, ethical, privacy and security aspects could not be fully explored.
- Due to the participation in the TIME4CS seminar, we gained an in-depth insight into the ETHNA project and discussed the possibility of an RRI offer using the JoinUs4Health platform to promote RRI.
- Ethical aspects as part of the JoinUs4Health concept are covered by WP2 (see manuscripts in preparation).

9.2 Work Package 2

9.2.1 Objectives and tasks

Objectives

1. Learning from and engaging with previous projects, both RRI and crowdsourcing projects
2. Set up an international panel of RRI and crowdsourcing experts as an online deliberative community, involving participants from 12 European countries and focussing on the institutional dimension of responsible innovation; the panel will convene three times (M6, M18, M30) via an online platform, commenting on input provided by the consortium
3. Develop a validated RRI methodology on the institutional level for consortium partners and future users

Tasks

Task 2.1: Systematic needs assessment and consultation of stakeholders

Task 2.2: Setting up the international RRI advisory panel

Task 2.3: Monitoring and advising activities in the other WPs

Task 2.4: Revision of conceptual framework

9.2.2 Actions performed

To Task 2.1: Systematic needs assessment and consultation of stakeholders

- Literature review and methodological reflections on RRI and crowdsourcing (cross cutting issues)

- Organizations of discussions with consortium partners, external stakeholders as well as at the 4th SwafS stakeholder forum organized by the ROSiE project and the Citizen science conference in Denmark (25-26/04/22)
- Co-lead of the 1st and lead of the 2nd and 3rd peer-reviewed manuscripts (1st partly published as Deliverable 1.1; 2nd and 3rd accessible as pre-prints)
- Presentation PCST 2023 (04/23): "Epistemologies of the crowd: considering positionality in citizen science"

To Task 2.2: Setting up the international RRI advisory panel

- Establishment of the RRI advisory panel: Invitation of five panel members in 2021 (Milestone 2.1 completed on 28/01/21) and two members in 2022, thus completing the panel with seven members in total
- Consultation of RRI advisory panel
- Organization of three consultations:
    - 16/06/21 with 5/5 members (Milestone 2.2; 31/07/21)
    - 10/06/22 with 6/7 members (Milestone 2.3: 30/07/22)
    - 11/09/23 with 6/7 members (Milestone 2.4; 30/09/23)

To Task 2.3: Monitoring and advising activities in the other WPs

- Mentoring of project partners throughout the project, e.g.
    - engagement in discussions during biweekly project meetings,
    - review of deliverables, especially D6.4, D5.1 and D5.2
- Extensive contributions to the Minor "Science for Society" with EMC

To Task 2.4: Revision of conceptual framework

- Ongoing reflection on the concept and processes based on exchanges and feedback received on barriers, opportunities and preferences, which will lead to Deliverables 2.2 and 2.3
- Preparation of four manuscripts, some of which form the basis for the PhD thesis of Ana Barbosa Mendes
    - Led by Hub Zwart: "Factors affecting engagement and uptake of RRI" (based on D2.3)
    - Led by Ana Barbosa Mendes: "Epistemologies of the crowd: considering positionality in citizen science"
    - Led by Ana Barbosa Mendes: "Potential and Pitfalls of Implementing Responsible Research and Innovation through Crowdsourcing"
    - Led by Ana Barbosa Mendes: "The 'projectification' of science is incompatible with Responsible Research and Innovation"

9.2.3   Relevant project outputs

- D2.1: "Methodological guidelines on implementing RRI and crowdsourcing in cohort research for partners" (submitted on 30/06/21)
- D2.2: "Benchmark methodology on implementing RRI and crowdsourcing for ongoing and future projects" (submitted on 26/07/23)
- D2.3: "Factors Affecting Engagement and Uptake of RRI" (submitted on 06/09/23)
- Two peer-reviewed preprints (rejected or withdrawn):
    - Ana Barbosa Mendes, Natalie Terzikhan (EMC) et al: Institutional changes through Responsible Research and Innovation (RRI) implementation in prospective cohort studies
    - Ana Barbosa Mendes, Silvan Licher (EMC) et al: Fostering organizational learning through responsible crowdsourcing in prospective cohort studies

- Three reports on the consultations of the international RRI panel (Milestones 2.2, 2.3 and 2.4)
- EUR Open and responsible Science award received as part of the Minor " From Science to Society" team (see Section 9.5)

9.2.4 Impacts achieved

- The provided recommendations from D2.2 and D2.3 (see below) provide useful advice for science and policy
- The extensive reflections with partners and the preparation of outputs such as the 2021 manuscripts contributed substantially to the mutual learning of partners
- The JoinUs4Health project as a form of radical citizen science provided an experimental
- RRI and ethical aspects are strongly embedded in the Minor "From Science to Society"
- Due to the intensive mentoring input, strengthening of RRI mind sets at the cohort institutions, especially at EMC
- Outputs of critical reflections on the underlying crowdsourcing methodology can contribute to future improvements
- Dissemination of methodological basis in relation to RRI and ethics

9.2.5 Reflections

WP2 monitored and interacted with the other WPs during the full course of the project, whilst other WPs serve as laboratories for validating the RRI crowdsourcing methodology. Unfortunately, it was not possible to fully test the methodological approach as community building on the platform is still in progress.

- RRI is an evolving concept: multiple interpretations: e.g., RRI keys (performance indicators) versus the AIRR process conception of RRI (other approaches, e.g. ELSA, Open and Responsible Science, etc.)
- We encountered the challenge of diverging ideas on what RRI consisted, the role that RRI had in the project and how it translated into the methodology. Also, the exchanges contributed to mutual learning, we encountered repeated frustrations in both sides
- The project was only based on virtual exchanges. A personal meetings amongst all partners could have promoted an earlier consensus on key aspects amongst partners.
- No clear pipeline on how methodological developments were to be tested and implemented, both within the project or within the participating institutions
- RRI is not a top-down protocol but a process of mutual learning, a path, a journey, a dialogue

Key recommendations for the future

Extracts from D2.2:

- Co-create their platform and their adapted methodology with potential users from the beginning of the project and continue to do so iteratively throughout their project
- Allow time to create a common language and vision between project partners to ensure the manner in which the methodology is adapted into the project's context realizes the shared goals in the project consortium
- Embedded their testing of the methodology into a structure of responsibility within institutions involved in the project
- Limited engagement in the platform as RRI laboratory
- Integrate systems thinking as part of the project methodologies to
- Promote mutual understanding of aims, assumptions and approaches amongst partners
- Engage stakeholders in co-creating the platform and methodology

Extracted from D2.3:

- decide on the scale of the implementation
- craft explicit policies for RRI
- provide RRI incentives both for individuals and for organisations
- create daily routines supporting and facilitating the daily work
- leverage internal and external change processes
- work with your external environment
- create organisational learning processes
- create pilot programs
- create a coherent mix of instruments and means
- make use of RRI champions

9.3   Work Package 3

9.3.1   Objectives and tasks

Objectives

1. Determine requirements for and design the project website and technical implementation of the platform
2. Develop the website and a secure technical platform to facilitate the exchange between citizen, cohort and associated representatives;
3. Test different approaches to generate high user satisfaction and attraction and apply technical features and approaches, which were perceived most effective (e.g. gamification, voting, working group interactions).

Tasks

Task 3.1 Design requirements for technical developments

Task 3.2 Develop technical means

Task 3.3 Explore different approaches and implement most useful features

9.3.2   Actions performed

Website

- a project website was publicly accessible since 03/09/21 (Milestone 3.1)
   - information on the JoinUs4Health project, consortium, activities and outputs
   - maintaining and adding website contents
- revision and update of the project website in the 2nd half of 2022
   - completely re-build of the news page for better user experience and simplification of the process for creating news blog articles
- production of a JoinUs4Health image film to enhance the reach and provide a quick explanation on the project concept
- 2nd revision of website in 2023 to
   - further optimize navigation and contents to enhance the user experience and
   - add the JoinUs4Health image film
- release of 26 news blog articles up to 08/12/23

Platform

- specification of technical requirements completed on 10/06/21 (Milestone 3.2)

- submission of D3.1 ("Report on the technical requirement including tools to be used for webinars") on 30/06/21
- launch of platform on 13/04/22 (Milestone 3.2)
  - allows implementation of the core steps of the JoinUs4Health concept
  - home page and four main pages (Suggestions, Topics, Tasks and Teams)
- continuous development of the platform based on user feedback (Task 3.3) to add more features and enhance the user experience, e.g.
  - optimization of thee landing page
  - integration of external tools (e.g. BigBlueButton, DeepL)
  - development of a mobile version of the platform
- use of the platform during exchanges with local, national and international stakeholders, which allowed us to gather feedback by scientists, citizens, policy makers as well as representatives from business/industry and the education community

9.3.3 Relevant project outputs

- three deliverables
- project website (https://joinus4health.eu)
  - 11 (sub-)pages, which describe the JoinUs4Health project, the consortium, activities and consortium outputs, activities through a news blog and the team
  - available in four languages: English, German, Polish and Dutch
  - adheres to requirements specified in D1.1 (Section 9.1)
- secure online platform including
  - terms of user, privacy statement (including automatic notification of user in case of updates)
  - tools to
    - allow Teams to meet virtually (BigBlueButton)
    - monitor user traffic on the platform and website: Webalizer and Matomo
- image film

9.3.4 Impacts achieved

- sustainable online communication infrastructure that allows the three cohorts to promote the brand of JoinUs4Health and engage people from their local societies in cohort research
- the platform is open source and can thus be implemented by other institutions on their own servers and adapted to their expectations and needs
- growing awareness of the JoinUs4Health platform (see Section 5.1)

9.3.5 Reflections

- design requirements for platform and website not co-created with stakeholders
- platform prototype not tested with stakeholders
- lack of in-depth testing of all features presents a risk; therefore, resources should be made available to ensure that any bugs related to existing feature are still addressed after the end of the funding period
- various features were proposed for future development, but could not yet be implemented yet, e.g.
  - visualization of cohort results based on a random sample with overlay of modelling results prepared by MUB
  - a page summarizing outputs produced across topics
- Changes in envisaged set-up (managed servers instead of own servers)
- Task 3.3 could only be partly done due to the low uptake of the platform, especially the Team interactions

- A mobile version of the platform will become available at the end of the project, which may also promote online engagement in the future.
- Platform developments continued until the end of the project.

9.4 Work Package 4

9.4.1 Objectives and tasks

Objectives

1. Conceptualize institutional changes corresponding with the specificity of the stakeholder, taking into account the barriers and capabilities of the institution in the context of involving citizens in the learning process - (Goal Development and Creation of Roadmap); this will also include definition of desired institutional changes in other stakeholders (e.g. local authorities, schools, NGOs) together with the roadmap of lobbying for these.
2. Implement institutional changes supported by appropriate internal legal acts (Cohort Centres) – (Implementation of immediate steps and long-term strategy)
3. Develop recommendations of institutional changes at the level of scientists, citizens, local authorities - support in creating pro-RRI attitudes - (Implementation of immediate steps and long-term strategy)
4. Evaluate results of institutional changes through exchange of experience between stakeholders and adaptation of possible best solutions in each from the centres – (Document Process and Results)

Tasks

- Task 3.1 Design of institutional changes in consultation with institutional leaders, researchers, clinicians and input from the citizen science board
- Task 3.2 Implementation of institutional changes
  - Engagement of citizens, pupils and other societal actors in all stages of the cohort research cycle
  - Semi-open access of cohort results to working groups; open access / transparency regarding the citizen science process, resulting materials and data dictionaries
  - Targeted communication and dissemination of results derived from the cohort studies and other scientific and non-scientific sources based on societal needs using traditional and non-traditional means
  - Management: Independent citizen science board at each cohort institution with input from researchers
  - Implementation of RRI in the cohort and associated institutions including alternative reward-based systems
  - Education: Junior Medical School, Honours Class, Masters in Health Science and Clinical Research, design and offer of online courses
- Task 3.3 Evaluation and documentation of institutional changes also aimed at creating a benchmark for future projects

9.4.2 Actions performed

- Design of institutional changes
- Platform
- Advisory boards
- Science communication
- Curriculum change (EMC)
- New RRI research line (EMC)
- Knowledge translation from cohort to society (MUB)

- RRI promotion and education
- Information events for different groups of stakeholders
- Evaluation of institutional changes

9.4.3 Relevant project outputs

Three deliverables

List of key recommendations for the successful implementation of institutional changes related to RRI projects:

- Strengthen Collaboration: Foster a culture of sharing and collaboration among cohort studies to facilitate a more unified approach to data management and access.

- Continuous Monitoring and Support: Establish mechanisms for ongoing monitoring and support to ensure sustained implementation of best practices and to address emerging challenges.

- Flexibility and Customization: Recognize and accommodate the diverse needs and capacities of different institutions, allowing for tailored approaches while maintaining core standards.

- Promote Education and Awareness: Invest in educational initiatives to highlight the importance of open access and user-friendly data resources, thereby enhancing the skill set of researchers and stakeholders.

- Prioritize Inclusive Governance: Emphasize the establishment of diverse and inclusive advisory bodies from the outset to ensure varied perspectives in decision-making.

- Commit to Continuous Evaluation: Implement a framework for regular assessment and refinement of governance structures to adapt to changing needs and challenges.

- Foster Open Communication and Collaboration: Encourage a culture of open dialogue and joint efforts among all stakeholders to enhance project effectiveness and stakeholder satisfaction.

- Adapt and Innovate Based on Experience: Utilize insights and experiences from past projects to inform and innovate governance strategies, ensuring they are responsive and effective.

- Verification of Engagement: Assess the platform's engagement potential comprehensively over time, especially in the context of increased user traffic and engagement.

- Sustaining Interest and Participation: Ensure sustained user interest and participation over time, considering innovative strategies to keep stakeholders actively involved and engaged.

- Facilitation Staff Engagement: Address the need for adequate staff and resources to manage the platform effectively and facilitate interaction and engagement.

- Promote Awareness and Accessibility: Increase efforts to promote the platform and its projects, ensuring it reaches a wider audience and remains accessible to all potential users.

- Long-term Visibility of Change: Recognize the need for continued efforts and long-term assessment to observe the real impact of changes on scientific literacy and the general perception of science.

- Challenges in Implementing RRI Rewards: Address the academic community's traditional evaluation systems and advocate for a cultural shift toward recognizing diverse forms of academic contributions.

- Need for Intensive Promotion and Education: Intensify promotion and education about the benefits of RRI to build understanding and support among scientists and university authorities.

9.4.4   Impacts achieved

1. Sustainability: Citizen Science Board as Bialystok PLUS is an important pillar for the future, with the possibility to extend its function to the whole MUB.

2. Advocating for Data Accessibility: System of dashboards for data presentation (Bialystok PLUS) will be created over the next 3 years with funding from the Ministry of Science (Poland); data dictionaries have been developed and will be implemented online on the new Bialystok PLUS website.

3. Promotion of RRI principles: Through educational and promotional initiatives, lay a solid foundation for demonstrating the real-world impact of RRI principles (RRI champions needed to motivate scientists).

4. Fostering public engagement: Significantly increased public engagement in the research process through various outreach activities and use of interactive platforms. The JoinUs4Health brand has become better known in Bialystok in recent months (especially among high school students), which is a great investment for future initiatives.

9.4.5   Reflections

Institutional change within the JoinUs4Health project is a very complex and comprehensive task due to the elaborate design of the project. Firstly, it is important to remember that not all institutional change has a formalised form, and often the change is already in the attitudes of part of the target community. Secondly, this type of change takes a long time to be finally confirmed and consolidated. Thirdly, the management structure of the JoinUs4Health project required, on the one hand, the division into work packages, which formally bound and committed their leaders, and, on the other hand, the involvement of the team in almost all work packages in order to achieve coherence. For this reason, a kind of institutional change was achieved (created) from components implemented in different packages and at different times. Nevertheless, the ambitious task of implementing at least 6 institutional changes in each of the cohort study sites seems to have been achieved. Not optimally, of course, but certainly each cohort is now in a process of transformation in which the RRI principles will play a key role.

9.5   Work Package 5

9.5.1   Objectives and tasks

Objectives

1. Map and critically appraise ongoing initiatives that utilize educational programs that aim for a sustainable engagement of citizens and society as a whole in science in EU through literature search

2. Summarize core curriculum for RRI and citizen science for researchers and healthcare professionals
3. Practically engage [high school, graduate and postgraduate] students in science through concepts of summer high schools in all participating institutions, leveraging expertise from experienced consortium partners, such as the 'Junior Medical School' and 'Erasmus Summer Programme' from NIHES
4. Develop and implement (online) courses and webinars specifically dedicated to RRI
5. Develop online courses of courses that are currently available at the epidemiological teaching faculty in Rotterdam (NIHES)

Tasks

Task 5.1 Mapping on-going initiatives at national, EU and international level

Task 5.2 Engagement of high school, graduate and postgraduate students

Task 5.3 Development and implementation of online courses and webinars on RRI

Task 5.4 Translation of existing science courses into online format

9.5.2 Actions performed

See D7.5 for further details.

- Designing and implementing a 10-week Minor programme open for bachelor students with various backgrounds: "From Science to Society" (EMC with support from EUR)
- Hosting and guiding two editions of Scientific Summer schools for high school students (EMC in collaboration with NIHES)
- School activities in Rotterdam
- School activities in Bialystok [13]
- Education activities in Germany
  - Two new facultative lectures on offer at UMG
  - Contribution to "I am a scientist" in 2022

9.5.3 Relevant project outputs

- Five deliverables
- Two editions of the 10week Minor programme "From Science to Society"[14] (higher than expected impact; most likely sustainable)
  - 2022: 12 students (from Erasmus University, Leiden University, Erasmus Medical centre and Erasmus University College)
  - 2023: 7 students (from Erasmus University, Erasmus Medical Centre and Erasmus University college)
- Contributor to the official Erasmus University podcast series[15]
- Significant role in the complete revision of the Erasmus MC medical curriculum, fuelled by our experience in the JoinUs4Health consortium
- RRI research line, led by Natalie Terzikhan, higher than expected impact, most likely sustainable
- Rotterdam Study Methods and COVID-19 sub-study design papers (23,24)

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[13] https://www.linkedin.com/posts/joinus4health_poland-activity-citizenscience-activity-7112792190044520449--c6n
[14] https://www.eur.nl/en/impactatthecore/science-society
[15] https://www.eur.nl/impactatthecore/aflevering-2-dr-silvan-licher-erasmusarts2030

- Bialystok: Preparation of lesson scenarios and podcasts[16]

9.5.4 Impacts achieved

- Fundamental change to the Erasmus MC medical curriculum (unexpected impact; highly sustainable), with more prominent focus on societal engagement of the next-generation physicians
- Creation of RRI champions
- Leading partners within the official Health Innovation Netherlands initiative, connecting health innovators with societal stakeholders to facilitate impact and change in space of strong support from EMC and regional partners

9.5.5 Reflections

Personal reflections

At first sight, a 3-year project feels sufficient and appropriate to facilitate the required institutional changes to better integrate and implement the RRI framework. Designing and planning deliverables around this aim felt natural three years ago, yet given changes at the institutional and national level in the realm of RRI, we had to revise planning for some of these deliverables. At the same time, we anticipated on this societal call for changing (the reward system of) science which led to unexpected yet highly desired outcomes in terms of RRI and institutional change. For example, we had never anticipated to have had such significant impact on the design and implementation of an entire new medical curriculum of the largest hospital in the Netherlands. Secondly, in a brief period of time we were nationally recognized as leading experts in the field of RRI, leading to several invitations to take place in expert committees to guide change and innovation from ivory towers to the societal battlefield (i.e. Case team leads for Health Innovation Netherlands). This recognition has been underlined by external parties multiple times in terms of awards and personal prices (Patient Award, Open Research Award, Gerrit-Jan Mulder price for the outstanding societal impact of the research project by high school (!) students).

Exemplary feedback by one of the students enrolled in the Minor "Science for Society" in 2023:

Exceptionally innovative! The minor has a unique approach to building new knowledge. while incorporating OPEN science and learning on how to generate impactful research. Additionally. the minor was eye-opening and facilitated critical thinking on topics which are important. but still remain unaddressed in science and society. The tutors of the minor had a very individual oriented approach tailored to the needs and interests of the students. In that way they could help with their expertise and bring us closer to what it feels like to be a researcher. I believe that this minor needs to be made mandatory for masters students as its potential deserves a part from the curriculum."

9.6 Work Package 6

9.6.1 Objectives and tasks

Objectives

1. Conceptualize implementation and creation of a participatory approach
2. Implement the communication and dissemination strategy
3. Evaluate of the execution of communication and dissemination strategies on key indicators

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[16] https://joinus4health.eu/free-scripts-for-teachers-citizen-power-ju4h/

Tasks

Task 6.1: Engagement of actors at the local level

Task 6.2: Engagement of actors at the national and international level

Task 6.3: Communication and dissemination

9.6.2 Actions performed

We recognized two major challenges when writing the Grant Agreement:

1. to build a sustainable and consistent online communication infrastructure;
2. to increase the number of people who are open to engagement in science-related activities at all levels, from ordinary awareness and non-rejection through liking and conviction, to participation and real input

9.6.3 Relevant project outputs

We submitted seven deliverables:

- D6.1 Events
- D6.2 Policy brief
- D6.3 Plan for communications, dissemination and community building
- D6.4 Communication and dissemination strategy
- D6.5 Standard operating procedure document (SOP) to engage high school students via the platform
- D6.6 Policy brief
- D6.7 Evaluation report on communication and dissemination strategy

9.6.4 Impacts achieved

The impact of communication and dissemination activities can be measured in a variety of ways, such as the number of events held, off-line meetings conducted, or online impact through social media. The best measure of the efforts made will be the fulfilment of most of the KPIs set at the beginning of the project regarding awareness, engagement and dissemination. Although it was not possible to fulfil those related to high user engagement on the platform, overall in the local community the JoinUs4Health brand is recognized by nearly one in five people and has a consistent image as expected.

Important achievements that will leave an impact include:

- a coherent social media strategy and profiles that will resonate during the sustainability phase of the project

- workshop lesson plans to make students aware of what RRI, crowdsourcing, cohort studies are and a tutorial for teachers on how to implement them.

- a series of podcasts recorded by high school students on the above topics.

9.6.5 Reflections

Undoubtedly, the main reflection that comes to mind at the end remains the issue of cooperation in an international consortium, where partners learn their work culture and the required standards. Those primarily responsible for the development, implementation and evaluation of the communication strategy did not foresee the fact of the very strict restrictions on the issue of personal data processing. Something that seemed obvious, i.e. tools that track users' web traffic in order to be able to realize the goals of the communication and dissemination strategy, turned out to be problematic from the legal side from the point of view of the platform administrator and indirectly translated into the failure to meet the KPIs associated with the online platform.

9.7   Work Package 7

9.7.1   Objectives and tasks

Objectives

1. Coordinate the consortium, manage administrative and financial aspects of the project,
2. Monitor the project activities
3. Evaluate the project's impact
4. Ensure sustainability of the project

Tasks

Task 7.1 Coordination of project partners

Task 7.2 Administrative and financial management

Task 7.3 Monitoring

Task 7.4 Evaluation

9.7.2   Actions performed

- Coordination: e.g. organization of biweekly and annual project meetings, overall financial administration, main contact point for EC project officer and SwafS project representatives
- Monitoring (see Section 4.1): Two questionnaires, one intervention study, user traffic on website and platform
- Evaluation: Two systems thinking workshops, application of the NEOH framework and the MICS impact evaluation tool
- Representation of the JoinUs4Health project at various meetings, e.g.
    o Several SwafS meetings
    o Resbios workshop in 12/23
    o Knowledge valorisation workshops
    o EU Citizen Science platform

9.7.3   Relevant project outputs

We submitted five deliverables, which are all publicly accessible. Two of these deliverables (D7.4 and D7.5) were added after the midterm review to document the lessons learnt in two extra deliverables:

Outputs:

- D7.2: Data management plan (submitted on 30/04/22)
- Baseline evaluation (04-08/21):

- o D7.1: Monitoring and evaluation framework (submitted on 31/08/21)
- o Draft systems map
- o Recommendations for collaboration amongst partners by WP2
- Interim evaluation (01-03/23)
  - o D7.4: Experiences as young consortium (submitted on 30/04/23)
  - o Revised systems map
  - o Narrative interim evaluation report
- Final evaluation (11-12/23)
  - o D7.3: Final M&E report (submitted on 31/12/23)
  - o D7.5: Experiences with citizen science (submitted on 31/12/23)

9.7.4 Impacts achieved

- documentation of lessons learnt provides useful resource for other SwafS projects, research performing organizations, policy makers and others
- the link between One Health and RRI may open new avenues for the future
- the project has informed other SwafS projects and stakeholders of the RRI community

9.7.5 Reflections

- Fewer full consortium meetings than envisaged (see D7.4)
  - o Details: No kick off meeting and only one instead of two annual meetings for the entire consortium
  - o Reasons: Competing time pressures, difficulties in finding a time with all WP leaders present and the short-term contract with the first project coordinator.
  - o Consequences: Missed opportunities to form joint vision on the project early on, define an evaluation framework, etc.
  - o Note: Biweekly meetings open to all partners took place
- Discrepancies in perspectives between cohort partners and RRI mentor for instance regarding the role of cohorts, the role of science communication, etc.
  - o From 06/22 to the beginning of 2023, we had intense discussions and reflections
  - o But we did not systematically strive to come to agreements and shared visions
  - o The systems thinking workshop were valuable elements in enhancing mutual understanding
  - o As a result, a degree of resignation may have arisen over time.
  - o Combined with a high work load in 2023 and the need to finalize project outputs, reflections have become less predominant in 2023.
- The Coordinator position was not continuously filled (see D7.4). Consequences:
  - o Several hand overs, lack of continuity, less chance to create sustainable RRI champions, high pressure on other staff within the department
  - o But also tremendous internal support strengthening understanding of and identification with the project
- In hindsight, NGOs should have been given a more predominant role
  - o Due to budget limitations three partners only had a minor role in the project, which limited their input
  - o Their role could have been highly valuable, for instance when designing the platform, revising the methodology and building an active community

10. Impact evaluation

10.1 MICS impact evaluation report

Figure 11 shows the impact scores resulting from the assessments of impact on society, governance, economy, environment and science. Recommendations are shown in Appendix 3 and discussed under Sections 10.2 to 10.6.

Impact Indicators		Impact score (max 42)	Average score (of projects on platform)
Society	Activeness	42	22
	Involvement	43	17
Governance	Policy	5	13
	Sustainable Development Goals	20	16
Economy	Economic productivity	42	13
	Financial sustainability	16	19
Environment	Environmental awareness	23	21
	Environmental footprint	10	13
Science	Scientific productivity	19	18
	Interdiscplinary science	33	21

Figure 11. MICS impact evaluation report: Rule-based scores comparing JoinUs4Health with the average of all projects on the MICS platform (https://mics.tools/projects/joinus4health).

10.2 Societal impact

Society is facing many challenges nowadays (e.g. wars, climate change, polarization of societies, Corona pandemic…). Therefore, it becomes even more imperative to change our way of working to become more responsive to societal needs, make benefits of cohort research more tangible to the local population and beyond and open the scientific process to input from societal stakeholders. It is still too early to assess the societal impact, but the concept, reflections, and institutional commitments are promising.

The SHIP study region is developing into a One Health hub, with one new institute (Helmholtz Institute for One Health, One Health Research Institute) besides existing important players in One Health (Friedrich Loeffler Institute, University Greifswald, University Medicine Greifswald) and important research consortia. In 01 or 02/24, we will organize a meeting with regional partners to discuss further potential to grow together at the regional level and discuss to what extent the JoinUs4Health platform and concept can add value to that process, also after the end of the funding period.

10.3 Democratic impact

Given our challenges in forming an active platform community, we have not yet applied self-administered questionnaires at various points of engagement. Therefore, we discuss the potential based on two examples where crowdsourcing was used to collate ideas:

Collation of suggestions was recently promoted as a valuable tool for EU policy making (25). The European Citizen Action Service (ECAS), an organization promoting democracy in the EU, carried out a consultative crowdsourcing exercise in ten European cities[17] between 01/22 and 01/23. An online platform allowed citizens to propose solutions. The aim was to collate input from the citizens on possible solutions to combat air pollution, which were to be shared with policy-makers. Elisa Lironi, programme director at ECAS, said that the idea behind the crowdsourcing exercise was to have a "real transnational participatory democracy experiment".

In JoinUs4Health, we collate suggestions, but more with a focus on the local level, given the focus on the cohort regions. The advantage of applying this process locally is that regional networks, (citizens') groups and initiatives can be connected based on proposed topics to jointly work on integrated solutions.

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[17] Amsterdam, Athens, Berlin, Brussels, Budapest, Burgas, Lisbon, Podgorica, Riga, and Tallinn

10.4 Economic impact

10.4.1 Cohort response

Opening up cohort research to society including non-scientific stakeholder groups (e.g. business, non-governmental organisations, public health authorities, education community, etc.) has the potential to increase response and thus produce higher value on investment. Our hypothesis is that response will increase by at least 7% (assuming 50% in the control group).

One of our early assumptions was that an individual may be more willing to participate in the cohort examinations given the possibility to directly engage with science and access cohort results. We assumed that the offer itself of being able to do so and the possibility of this individual discussing this option with others (around the dinner table, with friends) would increase the likelihood of this individual participating even if he/she was not interested to participate directly or had no time to do so.

As outlined in Section 5.2, we did not observe a significant difference in cohort response between individuals who received information on JoinUs4Health and those who did not receive any information over a period of 19 months, starting one month after the release of the platform (05/22) until the end of the project (11/23). The lack of a difference in cohort response may be contributed to different factors. It may be too early to expect an impact, given that the platform has not yet fully reached its potential. As a crowdsourcing platform without an active community behind it, we could not yet demonstrate the value of outputs through the engagement of people from various background and the direct access to scientific results, expertise and networks, e.g. the use of cohort results tailored to the question of interest. At this stage, it is difficult to predict if cohort response will differ in the future, once the platform has generated more value and the concept has arrived more deeply in the population.

10.4.2 Costs associated with institutional changes

Table 7 lists the costs with technical maintenance of website and platform

Table 7. Paid services by tools used for the JonUs4Health website and platform[18]

Service	Tool	Function	Costs / year (€)
Netcup [a]			
Server for webhosting	Website	Hosting	39
Managed private server	Platform	Hosting	575
Root-server for Matomo	Website and platform		39
Werk21			
BigBlueButton conference system	Platform	Virtual meetings	1,714
DeepL	Platform	Automated translation	300
WordPress-Plugin			
TranslatePress	Website	Automated translation	159
Total			**2,826**
Total excluding BigBlueButton conference system [b]			**1,112**

[a] Server costs will vary depending on the hosting provider used.
[b] BigBlueButton is not mandatory for the platform to function. Alternative options for virtual meetings exist, but would not be embedded within the platform infrastructure.

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[18] Links: Matomo: https://matomo.org/; DeepL: https://www.deepl.com/de/pro; TranslatePress: https://translatepress.com/; BigBlueButton: https://bigbluebutton.org/

Platform-related contents

- *Reviewer* role: In case of new submissions: Review suggestions and comments and decide on action (make public, contact author to discuss potential revision, consult advisory board, reject without further consultation)
- *Moderator* role: In case a platform user volunteers to facilitate a new topic (*Facilitator* role), the moderator provides background support (e.g. revision of initial contents, advice in case of questions or needs, support in outreach, consultation on the potential of using cohort research

Outreach activities

We are still at an early implementation phase. We had assumed that the opportunity of working with scientists and tailored cohort results would be sufficient of an incentive to create an active community during the 20 ½ months between platform release (13/04/22) and the end of the project, cut down short from 24 months due to a delay in releasing the platform (plan: 31/12/21). During that time, we expected an increase build-up in platform users through the wide outreach activities of the three cohort institutions.

10.5 Scientific impact

D7.5 (Experiences with Citizen Science) provides an overview of activities and network contacts that arose from the project. Please also refer to the other project deliverables, which provide further insights into the work done under the respective Work Packages.

10.5.1 Innovation, new knowledge and insights

In all three cohort regions, JoinUs4Health activities have created new connections with other academic groups and networks, as well as with non-academic actors.

Innovation via engagement

Business: Innovation potential of crowdsourcing has been recognized many years ago resulting in various applications of crowdsourcing. In science in contrast, the concept of crowdsourcing has rarely been applied. AUSTRIA found. This suggestion was promoted by Work Package 2 as an alternative entry point to the concept. Since no meaningful team interactions could be supported via the platform yet, the full potential of the concept could not yet be assessed.

10.5.2 Collaboration between science and society

D7.5 outlines for each project activity how the activity evolved, what connections arose from it and any potential plans or sustainable outcomes resulting from it.

The concept and platform offer an interface where societal groups and individuals can reach out to the community and science, but also where scientists can initiate exchanges (for example as part of participatory approaches), open plans or findings for discussion or simply share key messages considered relevant for society based on the knowledge and database created through the cohorts.

10.5.3 Scientific outputs (publications, conferences)

Number of accepted manuscripts: 1

JoinUs4Health is mentioned in the update on the Rotterdam Study, which has been accepted by the European Journal of Epidemiology[24]. This publication is likely to be highly influential within the

scientific community based on the number of citations of previous Rotterdam Study papers. As part of this Rotterdam Study update, 3000+ characters (after removing links; excluding spaces) are dedicated to RRI and JoinUs4Health. Thanks to the EMC team for this wonderful achievement!

Number of withdrawn or rejected scientific manuscripts: 3

For three of these manuscripts, we received one round of reviewer comments, after which the manuscript was rejected (n = 1), rewritten (n = 1) or withdrawn (n = 1). The preparation of these manuscripts and exchanges amongst co-authors in the process of it as well as the reviewer's comments provided valuable input and helped focussing our methodological development in the light of literature and other sources.

1. Birgit Schauer and Hub Zwart: "Crowdsourcing as a method to foster inclusive innovation". Submitted to Journal of Responsible Innovation Submitted in 03/21; rejected in 09/21
2. Ana Barbosa Mendes, Natalie Terzikhan et al.(5): "Institutional changes through Responsible Research and Innovation (RRI) implementation in prospective cohort studies". Submitted to The Learning Organisation, Special Issue on "Institutional change" (abstract: 01/21; manuscript: 07/21); request for major revision; decision to re-submit as manuscript with renewed focus (see next item)
3. Ana Barbosa Mendes, Silvan Licher et al. (6): "Institutional changes through Responsible Research and Innovation (RRI) implementation in prospective cohort studies". Submitted to The Learning Organisation, Special Issue on "Institutional change" in 02/2022; request for major revision resulting in the withdrawal of the manuscript in 04/2022

Number of submitted manuscripts (review in process): 1

For one submitted manuscript the review process is ongoing.

Number of manuscripts currently in preparation: 2

Two further manuscripts by EUR are in preparation.

Number of scientific conferences: 11 (+1 in 2024)

See Table 9 for details:

- UMG: 7
- EMC and EUR: 2 each
- MUB: 3 and 1 more accepted for 2024

Once contribution is not counted (greyed out) as JoinUs4Health was mentioned, but not the focus.

Limitations

In the Grant Agreement, we hypothesized that the project could be implemented purely online (quote GA: Therefore, no budget for in-person meeting consortium or presentations)

Due to the need to remain within the overall budget and our claim that the project could be implemented purely online, we did not budget any travel expenditures including conference attendances. Ana Barbosa Mendes (EUR) successfully applied for a scholarship to attend the meeting in Denmark (26).

Due to COVID-restrictions early on and lack of dedicated funds, more conference contributions were delivered online (n = 7) than in-person (n = 4). Experience shows that in-person attendance of conferences offer many opportunities for follow-up and networking. Hence, online contributions may

have resulted in opportunities to create new networks, obtain feedback on and raise awareness for JoinUs4Health.

Table 8. Number of scientific outputs by year and type of output.

Type	Details	2021	2022	2023	2024	Total
Manuscripts						
	Withdrawn or rejected	2	1	0	na	**3**
	Under review	na	na	1	na	**1**
	In preparation	na	na	na	(2)	**(2)**
Conference contributions						
	Oral	3	2	2	(1)	**7**
	Poster	0	0	1	(0)	**1**
	Other	0	3	0	(0)	**3**
Total		**5**	**6**	**4**	**(3)**	**16**

na: Not applicable

10.5.4 Awards

Patient participation award (Dutch Lung Foundation)[19] – 2021

Financial award: 15,000 Euros

Receipt of the Patient participation award by the Dutch Lung Foundation. For our research project on the epidemiology of multimorbidity, we received this prestigious Award, as recognition for the active involvement and contribution of patients in our research.

Vindex Societatis Responsiblitatis Universitatis" – 2023

Award for the best presentation "JoinUs4Health – how cohort studies engage the local community in health action" (27) at the national conference "Socially Responsible – Examples of Good Practice".

EUR Open and responsible Science award - 2023

Extract from website[20]:

"Open Education: 'From Science to Society' Course Pioneers Open Education for Responsible Research and Innovation

For Open Education, the course 'From Science to Society' and its coordinator, Natalie Terzikhan and team, alongside the **JoinUs4Health consortium** at Erasmus MC, was awarded. This course has been recognized for its role in shaping a future-ready generation of scientists based on the Responsible Research and Innovation (RRI) philosophy. The interdisciplinary approach and collaboration with multiple universities were highlighted by the jury for their substantial impact on society and their contributions to educational innovation."

Source: https://www.linkedin.com/posts/natalie-t-0b9b5421_rri-openscience-stakeholderengagement-activity-7124443804232769536-SvZz/

10.5.5 Summary of recommendations generated via the MICS tool

Even though no specific recommendations were made via the MICS tool ("Keep up the good work".) there are many lessons learnt and avenues of improvements or simple needs to keep going. All of this requires resources. So to keep up the good work, resources need to be kept in mind. Simply leaving the platform technically open without any meaningful form of engagement does not reflect a change in mindset towards the benefits of and needs for RRI and transdisciplinarity. RRI champions should be nurtured within each institution to have someone who drives the concept internally. This person should have dedicated time to do so and be willing to locally engage also in offline activities.

Table 9. Overview of conference contributions

fid	Month	Name of conference	Country	Affiliation (presenting author)	Title (reference)	Type	Format
1	03/21	Dutch Citizen Science conference (Health RI)	NL	EMC / NL (Silvan Licher)	Implementing personalized health in co-creation with citizens and scientists: leveraging infrastructure and health data from existing cohort studies - the JoinUs4Health Consortium (28)	Oral	Online
2	06/21	Dutch Epidemiological Conference (WEON)	NL	EUR / NL		Oral	Online
3	09/21	16th annual meeting of the German Society of Epidemiologists	DE	UMG / DE (Birgit Schauer)	JoinUs4Health: Three cohorts (SHIP, Rotterdam Study and Bialystok PLUS) and their pathway to Responsible Research and Innovation via Crowdsourcing (29)	Oral	Online
4	04/22	Engaging Citizen Science conference	DK	EUR / NL (Ana Barbosa Mendes)	Stimulating deep co-creation in responsible crowdsourcing: the case of JoinUs4Health (26)	Round-table discussion	In-person
5	04/22	Helmholtz Institute for One Health Conference	DE	UMG / DE (Andrea Camila Diaz Perez)	Striving towards better zoonosis prevention through Responsible Crowdsourcing: SHIP-Next module One Health meets JoinUs4Health (30)	Oral	Online
6	04/22	Epi Days	DE	UMG / DE (Birgit Schauer)	[Population-based examinations of humans and animals in the Study of Health in Pomerania (SHIP)] (31)	Oral	Online
7	05/22	Open Innovation in Science Research Conference	AT	UMG / DE (Birgit Schauer)	Converging Responsible Research and Innovation and crowdsourcing in prospective cohort studies (JoinUs4Health) (32)	Platform demo	Online
8	10/22	17th annual meeting of the German Society of Epidemiologists	DE	UMG / DE (Birgit Schauer)	Operationalising Responsible Research and Innovation through Crowdsourcing (JoinUs4Health): Experiences and lessons learnt during the first months of platform implementation (33)	Oral	Online
9	10/22	One Health C@mp	DE	UMG / DE (Birgit Schauer)	Crowdsourcing as a method to promote Responsible Research and Innovation in cohort research (34)	Workshop & panel member	Online
10	09/23	18th annual meeting of the German Society of Epidemiologists	DE	UMG / DE (Johanna Dups-Bergmann)	Exploring the process of co-creating causal-loop diagrams in the evaluation of a novel project combining crowd sourcing and Responsible Research and Innovation (35)	Poster	In-person

fid	Month	Name of conference	Country	Affiliation (presenting author)	Title (reference)	Type	Format
11	10/23	"Socially Responsible - Examples of Good Practice" Conference	PL	MUB / PL (Pawel Sowa)	JoinUs4Health – how cohort studies engage the local community in health action (27)	Oral	In-person
12a	12/23	Towards Comprehensive Population Studies II	PL	MUB / PL (Karol Kaminski)	The development of the BIALYSTOK PLUS project (8)	Oral	In-person
12b			PL	EMC / NL (Natalie Terzikhan)	How the Rotterdam Study adapts to the changing science and society (9)	Oral	In-person
12c			PL	EMC / NL (Arfan M. Ikram)	[The main challenges and opportunities for populations studies in 5, 15 and 25 years] (7)	Oral	In-person
[13]	04/24	ECSA Conference	AT	MUB / PL (Pawel Sowa)	JoinUs4Health: the challenging path of multiple interdependencies of institutional change (36)	Oral	To be decided

Grey font colour: JoinUs4Health was not the central aspect of the presentation; title in brackets: Original language other than English

10.6 Environmental impact

10.6.1 Summary

Environmental impact often only becomes apparent after a long time (REFF). Therefore, this section refers rather to the potential future impact of JoinUs4Health activities related to environmental aspects (abstracts: See D7.5):

*Note: **Topics numbers** are assigned solely for this report and refer to the numbering in **Table 11**.*

- Nature based topics were two of the earliest platform topics
  - o 'Gardening for health' (Topics 13) and 'Forest bathing' (Topic 14)
  - o These two topics led to the highest number of follow-up activities
- Furthermore, two of the three topics arising from the digital workshop series (two workshops in 06/23 & two workshops in 12/23) with representatives from public health authorities related to climate change, i.e.
  - o Topic 2 ('Sun protection competence') and Topic 4 ('Climate change and health')
  - o It could be argued that Topic 3 ('Mental health of young people') could indirectly also be linked to climate change
- Nature-based approaches have since entered the focus of cohorts in Bialystok PLUS and SHIP, partly due to JoinUs4Health related activities and new network contacts
  - o promotion of RRI during the formation stage of the consortium
  - o contributions to two T!Raum proposals
  - o establishment of new contact in Germany with One Health Research Centre which resulted in
    - ▪ participation in a Biodiversa+ call (stage 1)
    - ▪ OHRC is now partner in EU project and is keen to use the platform for this project and other activities
    - ▪ One activity is currently in preparation: online-questionnaire to be sent to schools to assess access to green space (single-response per school)
  - o due to JOinUs4Health: In Bialystok, nature-base approaches have come to the foreground (8)
- largely independent of JoinUs4Health:
  - o emergence of SHIP cohort region into a One Health Hub given
    - ▪ the existing strong expertise in this area and
    - ▪ the emergence of new institutions (Helmholtz Institute for One Health; HIOH) and consortia (T!Raum, which is 9-year project to promote One Health approaches in the region; HIOH seed projects)
    - ▪ this emerging One Health Hub achieves a much stronger linkage of various regional players in the region, including environmental partners
    - ▪ given the close links between One Health and RRI, the region offers considerable potential to promote the tool and concept in the region in the future
  - o UMG cardiologists have become involved in proposals on nature-based approaches (EvideNT call)

10.6.2 Environmental impact of the project

By creating an **online** infrastructure to promote Responsible Research and Innovation through crowdsourcing and open up cohort research to local societies, we provide opportunities for exchanges without the need for in-person meetings and thus travel-related environmental impact. Furthermore, information can be circulated more readily online, which may otherwise have been distributed as print material.

11. Evaluation in relation to RRI keys, MoRRI and SDG indicators

11.1 RRI keys and MoRRI

This section provides a narrative overview in relation to the five RRI keys Public engagement, Science education, Gender equality, Ethics and Open Access. For JoinUs4Health, we reasoned that the RRI process dimensions are more suitable to the JoinUs4Health concept in general than the RRI keys (D2.2).

The application of the NEOH framework provided valuable insights regarding the areas Thinking, planning, working, sharing, learning and systemic evaluation. Due to our concerted efforts to promote engagement up to the very end of the project, we have not yet systematically assessed MoRRI indicators yet.

In this report, we primarily list relevant outputs and refer to respective sections in the report. We will discuss as a consortium in early 2024 to what extent to survey instruments can still be applied. Results can be published in an updated version of this deliverable.

11.1.1 Public engagement (PE)

The project reached out to a wide range of stakeholders (see Section 9.6) via various means. Dedicated offline activities were only carried out in the Bialystok region as we had assumed that we could work predominantly online in the other two cohort regions. In Rotterdam, little efforts were made to promote the platform as the focus of WP5 was education. Therefore, we tested a highly innovative concept in two study regions, which both have not had a lot of exposure to citizen science:

Extracts from a recent conference contribution by Natalie Terzikhan (9):

- But "we should not make the mistake to assume that people are ready to contribute. In Holland people are different than people in Germany and Poland. We should not assume anything for citizens. In order to be inclusive, we need to sit and talk to them.
- Although RRI has been promoted for over 10 years, it initially appears complex. It took me a few months to digest this idea. Now I cannot stop talking about it.
- RRI is a strategy as a way of working.
- The JoinUs4Health platform is like a virtual science shop. It is building up.
- Digitalization versus social support: Relationship building and personal connections are important, to be there as a community for citizens. It is important to come closer to citizens and get them to talk to you.

Extracts from a recent conference contribution by Karol Kaminski (8):

In fact, it is hard work to encourage people to participate. Actors and facilitator are needed. We need an attitude amongst scientists to appreciate the value of openness. Then we need people to promote the knowledge transfer, enriching the population. But it must be bidirectional. Citizens need to be activated to actively participate in science. But we need people in the middle. That requires effort and money.

Therefore, we can very much confirm challenges shared after an EU-wide crowdsourcing exercise in pilot cities (25):

- *"According to Petko Georgiev, director of ProInfo in Bulgaria, challenges include "mobilising sufficient resources, retaining citizens' attention over a long period of time and explaining how the process works and what its impact is". Hence, sustained investment of efforts will be needed from the cohorts or their regional partners to build a sustainable, active community with some Contributors advancing in their*

experience in applying RRI approaches and thus being able to take on a Moderator role. RRI is about relationship building, and that takes time.

- *Moreover, being a pan-European experiment involving cities with different civic culture and media landscape, "one-size-fits-all policies would never work in such a diverse environment" Georgiev said, pointing to the need for different campaigns to promote the experiment and encourage citizen participation.*
- *Tessel Renzenbrink, co-director of Netwerk Democratie in the Netherlands, said it is important to combine online and offline participation, to make sure everyone has the opportunity to take part in the process.*"

Therefore, sustained investment is needed to promote meaningful interactions in line with RRI. This requires also expertise in areas such as systems thinking, co-creation and facilitation. Cohort staff should be provided with opportunities to learn in these areas and from others with experience who can provide mentoring support.

11.1.2 Science education (SLSE)

The project has produced impacts far beyond what we had initially expected. See Section 9.5 for details.

11.1.3 Gender equality (GE)

Gender equality plan

The universities of all three cohort institutions (including the mentoring partner EUR) have gender equality plans in place: UMG[21], MUB[22], EUR/EMC[23]

Promotion of gender content in research

Gender / diversity was addressed as part of at least three initiatives, all of which were led by Dutch consortium partners:

1. *EMC: Laureate of a Gender in Research Fellowship by the Dutch Research council - 2021*

As a laureate of the prestigious Gender in Research Fellowship 2021 from the Dutch Research Council, Silvan Licher has developed expertise to adapt study design and its analyses to take into account the diversity of the (study) population. He leveraged the acquired skill and knowledge within the JoinUs4Health consortium to aid him in operationalizing gender in an existing cohort study, and to design and organize webinars for participants of the cohort in an inclusive manner[24].

Promoting diversity and epistemic inclusion is a key area of interest of EUR (lead of WP2). Reflections amongst partners most often became strained when discussing the role of scientists as part of the JoinUs4Health concept, whether they should or should not have a role in the advisory board or whether science communication has a place, as it is a top-down activity where scientist act in the role of an expert.

Initially we tried to promote mainly a bottom-up approach, inviting people to come to the platform with suggestions and work on those which receive a high level of input. But we were trying to wait

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[21] https://www.medizin.uni-greifswald.de/fileadmin/user_upload/Gleichstellungsbuero/GEP_%C3%BCberarbeitet_11.01.2022_final_Unterschrift.pdf
[22] https://www.umb.edu.pl/en/rowni/plan_rownosci_plci
[23] https://www.eur.nl/media/92665
[24] https://www.ergo-onderzoek.nl/Nieuws/webinars

for the users, but in fact our outreach activities have not been successful in bringing enough Contributors to the platform.

2. *EUR: Ana Barbosa Mendes placed a focus on diversity in her PhD research*

See Section 9.2

3. *EMC & EUR: Gender was promoted as part of the Minor programme (see Section 9.5)*
4. *Promotion of JoinUs4Health as used case for the ETHNA project as part of a TIME4CS webinar (see Section 9.1)*

11.1.4 Ethics (E)

- E1 (Ethics at the level of Universities /   recognition of contribution, pyramid system - upgrade in experience levels, ethics advisors from various groups of stakeholders);

11.1.5 Open access (OA)

- OA3 (Social media outreach / see WP5), OA6 (RPO support structures for researchers / incentives for data sharing, RRI training and engagement via the platform and other means)

11.1.6 Governance (GOV)

Based on a recent conference contribution by Natalie Terzikhan (EMC) (9):

It is important to invest into infrastructure, education and research simultaneously. It may take several years to get ready. But we are all reaching a lot by investing. We are still not there that the society understands why this is important. It is not enough yet. We need to make sure that people understand the relevance of it and then it will roll. Society will come closer and will participate more and response rate will increase. But it takes more time.

We need RRI and Open Science champions, people on the ground who take the idea of RRI further who are able to connect everything together (education, research, infrastructure, community building), Make sure that you have champions everywhere: Otherwise it may take a long time to achieve a change in mindset

11.2 Sustainable Development goals

The JoinUs4Health project contributes predominantly to four Sustainable Development Goals, i.e.

- SDG3: Good Health and Wellbeing, by
    - providing the platform
    - continuously collating health-related suggestions, which are open to anybody
    - supporting interested Contributors
    - crowdsourcing internally (within cohorts) or through associated partner institutes or networks upon demand
- SDG4: Quality Education by
    - various education activities (see Section 9.5)
    - various open access teaching and learning materials and English and Polish
- SDG11: Sustainable Cities and Communities by
    - promoting topics which may not receive sufficient attention in the scientific community otherwise, e.g. forest bathing, community gardens
    - opening cohort research to individuals, institutions and networks active in that area who can utilize descriptive results based on cohort data (if available) to explore specific questions

- SDG16: Peace, Justice and Strong Institution by
  - strengthening democracy

12. Sustainability

12.1 JoinUs4Health

Most of the project outputs are open access and thus provide a valuable basis for future projects, scientists and interested individuals. We have created the infrastructure to collate suggestions, promote topics, meet virtually (BigBlueButton) and work together via tasks or teams in a secure environment with the support of a designated facilitator (any platform user) and moderator (user with experience in RRI).

New courses (Minor Science with and for Society), lesson materials and lesson plans provide important insights and materials for formal and informal education activities. Our YouTube videos as well as the contents on the platform (suggestions, topics, contents) can inspire others, potentially having a cross-fertilizing effect on future projects and initiatives.

The advisory boards will be continued in all three cohort regions, but at different levels of intensities. Including new perspectives in cohort research in such an advisory role is new for all three cohorts and will continue to provide valuable insights.

During the three-year funding period, we have established valuable regional collaborations, which we will continue to nurture and hopefully expanded. Sustained efforts will be needed, in higher intensity than initially envisaged due to the efforts required for meaningful engagements of stakeholders. Generally, medical universities are high pressure environments. We tried repeatedly to mobilise researchers or engage them in meetings. Scientists are often pressed for time. Time is a luxury, in constant demand from various directions. Therefore, freeing resources and providing incentives will be key to make JoinUs4Health a sustained success.

The financial challenges faced in academia at current times (Section 6.1) make it harder to free resources in an already stretched environment. Projects: JoinUs4Health is part of one approved project (CIFLY under T!Raum) and one application (Biodiversa+ call). Furthermore, we were invited to join a potential COST Action in 2024 with focus on systems thinking (application deadline: 10/24). Projects: JoinUs4Health is part of one approved project (CIFLY under T!Raum) and one application (Biodiversa+ call). Furthermore, we were invited to join a potential COST Action in 2024 with focus on systems thinking (application deadline: 10/24).

12.2 Future temporal settings

The COVID-19 pandemic has revealed multiple vulnerabilities and caused a global trauma, which can still be felt in many areas (e.g. increase in loneliness and mental illness; change of trust in science and of political landscape). After decades of relatively stable peace globally, we are witnessing two major conflicts in Ukraine and Gaza, which have shaken our understanding of the global order and values. Polarization can be felt in many areas. The cost of living crises adds to the pain and insecurities felt by many. Opening up towards each other, breaking down barriers and connecting existing or emerging "bubbles" of people seems more important than ever as we see our world enter a phase of major uncertainties. Conflict and polarization cannot be an answer.

The search for integrated health approaches benefits hugely from systems thinking and transdisciplinary approaches. We need to come together, share values and experiences, open our minds to recognize the value of combining different knowledge sources and perspective. We are on a good path. SwafS projects have produced a range of materials and recommendations, which can be used and adapted.

But RRI is a process, which needs time. It needs to be nurtured from within, for instance by allocating dedicated RRI officer who can act as RRI champion within the institution and has the top-level support to mobilize other staff members within the institution. In case of running the platform, IT resources are also required not just for regular maintenance, but also for potential trouble shooting. Many universities are in precarious financial situations leading to staff losses and major budget constraints. This can act as a major impediment to approve already limited resources to invest in RRI activities.

Institutional incentives should also be generated for individual departments and scientists. So far, we have not yet managed to institutionalize incentives in a formal manner. But the top-level support at EMC and MUB is promising that institutional incentives will follow in the future.

12.3 Future of RRI

JoinUs4Health has contributed a valuable basis for future projects through

- the project outputs, most of which are open access
- various other materials and contents developed
- an open source platform, which can be adapted by other institutions
- a detailed documentation of experiences with citizen science in D7.5
- our contributions listed under Scientific Impact
- our contributions to EU-led initiatives such as the knowledge valorisation work.

Furthermore, a dedicated section on RRI and JoinUs4Health was included in the scientific publication providing an update on the Rotterdam Study (REFF) and leading representatives of the Rotterdam Study (7) and Bialystok PLUS (8) have expressed high-level support of the concept at the European Conference on cohort studies, which takes place only once every five years.

An important next step is the continuation of the institutional changes to continue leveraging the potential of opening cohort research to (local) societies. A change in mind set takes time and needs to take place not just amongst scientists but also societal stakeholders. Cohort studies are long-term studies by design. Hence, they provide a long-term opportunity to engage local societies.

One concern of cohort research is to influence the individual in their behaviour through the cohort examination itself, which in turn would cause bias in follow-up examination. However, if we feed cohort results back to the local population, without providing recommendations to individual cohort participants, we can influence the population at large, not selectively cohort participants only.

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13. Discussion

13.1 Overall discussion

The lack of an active community prevented us to truly test the crowdsourcing concepts and demonstrate the potential benefits. Several of the very early assumptions had to be revisited. But this report illustrates that as a consortium as a whole, we have made major achievements in different areas.

We did not observe a change in cohort response: So the assumption that simply opening cohort research to society, i.e. offering the opportunity to engage in science or simply view contributions by fellow citizens would increase response, has so far not proven correct yet. It can be argued that a platform with little activity does not yet express the true potential of the concept as no actual case application could be promoted as use case demonstrating the value of the concept from start to finish. From the cohorts' perspective, opening up the scientific process also means investing resources in engagement, providing training to staff and generating incentives and acknowledgements for scientists and other staff members of the cohort institutions, their medical universities they are embedded in and external institutions. Embedding teaching on RRI, systems thinking, co-creation methods and science communication is an investment, which could contribute to a sustained shift in mindset of the scientific community.

In Bialystok especially a raising awareness becomes tangible. Two advisory boards are meeting regularly to discuss aspects in relation to Bialystok PLUS. The three year funding period has made it possible to lay the foundation. The actual success of the platform itself will largely depend on the upcoming years. Will the awareness of the JoinUs4Health brand in the region increase? Will more and more people be willing to invest time or share experiences and suggestions in relation to health? Will there be enough support from the scientific community to support meaningful exchanges and provide cohort results tailored to the need of Teams. Will we be able to continue the two roles of facilitator and moderator?

The crowdsourcing concept promoted as part of JoinUs4Health is a form of radical citizen science. Therefore, its challenges in recruiting input cannot be extrapolated to citizen science activities in general. We received feedback that it was not intuitive what to do on the platform, and that the concept was difficult to comprehend. Furthermore, a crowdsourcing endeavour without an active community behind it is not very encouraging for a potential newcomer. But we do recommend to combine on- and offline activities as relation-ship building, especially at the early phase of team formation, and clarification of potential questions or concerns is easier in face-to-face settings.

We have tried various avenues, but have not yet succeeded in the cohort regions of SHIP (North-eastern Germany) and Bialystok PLUS (Eastern Poland). Both these regions are in a lot of ways similar, i.e. they both are relatively rural areas with low population densities and relatively low socio-economic status compared to other regions in their countries. We could not yet test the concept in Rotterdam as EMC was predominantly focussed on promoting RRI as part of formal and informal education. Therefore, it is difficult to judge to what extent regional differences

13.2 Revision of assumptions

Despite a wide range of activities to create awareness of the project, amongst citizens, local networks and scientists, we have not yet reached a critical threshold, where a sufficient number of Contributors come together via the platform to work together on health-related topics. One public health representative recently stated that the concept is thought "too big", we should start off with smaller steps. In a way, the smaller steps are the Topics. What the crowdsourcing concept can

achieve is to connect these smaller steps, cross-fertilize, learn from each other and have an opportunity to also engage in critical dialogues.

What we have achieved is a collation of suggestions and topics. These examples can be used to clarify the concept better, for example by defining different pathways of potential Team-level interactions and performing a stakeholder analysis. This could for example be a Task for a student project, during which the platform is used to engage citizens in the process.

Surprisingly, the incentive of applying for cohort results tailored to the topic of interest was only applied as part of the workshop series with public health officials as no Team has formed on the platform yet. For the workshop with public health representatives in Germany, exploratory analyses were performed (descriptives, simple regression model) and presented as basis for discussion. However, it is a time-consuming process to prepare the data for analysis and perform simple statistics. So this offer can only be granted in selected cases or if dedicated staff resources are created within the institution who is mainly responsible for responding to Team requests (given approval by advisory boards) and liaise with relevant cohort representatives in planning the analyses and interpreting results.

As the actual crowdsourcing concept was only promoted in Poland and Germany (see Section 5.1), we cannot judge transferability to EU Member States that differ from these regions. Both the SHIP and Bialystok PLUS cohort regions are amongst the least populated regions with a comparatively low socio-economic status and education level compared to other regions of their country. Therefore, we missed an opportunity to test out the concept in regions / countries with a population who may be more willing to engage in a crowdsourcing initiative. In hindsight, granting a larger budget to MDOG and NDF in The Netherlands and APH in Germany would have allowed us to compare the concept in different settings as we could have mobilized more effectively in The Netherlands (MDOG and NDF) and other regions in Germany (APH).

Conclusion: Given the problems in recruiting sufficient Contributors to date, we are not yet in the position to judge to what extent these assumptions were justified or not. A systematic reflection on these assumptions in the light of ongoing experience would be a valuable task for the future.

13.3 Potential risks

It is important to note, that promoting such a crowdsourcing initiative without systematic efforts to engage marginalized or lower socio-economic groups may actually lead to a biased increase in response. Our experience shows that people with higher educational background (e.g. people who are already working in science or have relatives working at the medical University, students) are more likely to engage spontaneously than people from the general population. Therefore, efforts should be made to reach out specifically to groups that are underrepresented in the cohorts and work on topics that are of interest not just to people who spontaneously volunteer, but to people who may be harder to engage initially. Therefore, designated staff resources are important to not just offer the platform, but actually invest efforts to bring the platform to the people who are hard to reach. At the same time, diversity is key for RRI. It needs to be further explored if diversity needs to be promoted within the individual team at all times or if it is ok to let some teams work in their bubble (not everyone wants to engage with "others") and promote diversity by letting multiple teams work on the same topic and then interact at the end.

Another risk is that cohort institutions become seen as politically influenced for instance by

- approaching predominantly certain groups, e.g. as these groups are easier to engage (e.g. climate activists)
- promoting or supporting topics that are seen as controversial by some (e.g. vaccination, climate change) or

- taking sides and openly debating controversial topics with societal stakeholders supporting one side, but not allowing critical voices.

Hence, such an open crowdsourcing concept can potentially damage the cohort's reputation amongst certain population groups, which may already be reluctant to participate in cohort examinations.

Therefore, we consider it as important to preserve the role of Moderator and Facilitator, where the Moderator acts like a mentor without being in the centre of discussions. If controversial aspects occur, the advisory boards and the scientific steering committees of the cohort institutions can be consulted. The Climate Change topic has produced negative comments on social media (see D7.5). It is a learning process, also for the cohorts, how to deal with different contributions and how to ensure diversity and representation of different voices within the community even though some might be critical or confrontational

In conclusion, the cohort institutions should try to preserve their independence and should be open towards taking into account different types of evidence, perspectives and experiences. We are facing highly complex problems, which require all of us to listen with an open mind.

13.4 Comparison of the NEOH and MICS evaluation tools

REFER TO When (2021): Impact assessment of citizen science: state of the art and guiding principles for a consolidated approach

RRI and One Health share similar perspectives and approaches: Both

- aim for transdisciplinary approaches inviting stakeholders from different perspectives and backgrounds to engage in the search for integrative health approaches through innovative methods such as co-creation and systems thinking
- aim to apply a holistic approach looking at the system as a whole and combining different knowledge sources; systems thinking is considered a key domain in One Health and RRI and should therefore be considered a key approach by future initiatives and consortia
- The RRI and One Health communities are ever growing. To be effective, we need to reach more people. Potential benefits arise from illustrating how these communities are connected and can integrate their efforts.

Based on the author's personal assessment, the NEOH spreadsheets are applicable to integrated health approaches as they appear to complement the context of RRI equally to the context of OH. It should be further explored

- to what extent
  - the OH-ness is translatable into RRI-ness and
  - the NEOH evaluation framework is applicable to RRI initiatives as a whole
- how OH and RRI communities can be connected with the aim to create synergies and mutual learning opportunities

13.5 Outlook

A shortcoming of this Final M&E report is that partners had no time yet to revise the final draft prior to submission. In 01 and 02/2024, we will invite partners, advisory board members and interested stakeholders (e.g. citizens, SwafS or EU representatives) to provide feedback either by joining a designated workshop, a bilateral meeting or providing written feedback. In 01/2024, we will also translate the 2nd policy brief (D6.6) into all four languages and invite platform users to provide feedback.

Furthermore, we have not yet had time to embed the evaluation adequately in literature. It will be valuable to publish the evaluation results following in-depth consultations with partners and interested stakeholders and taking into account evidence from scientific literature, SwafS projects and other sources.

Future needs:

- Systematic activities to promote community building (e.g. monthly radio show coupled with on- and offline events)
- Platform: Further testing, potential advancements
- Dedicated staff at the cohort and regional partner institutions, ideally with experience in RRI and systems thinking
- Develop a publication strategy
- Formation of future consortia to build on the foundation established via the activities as part of the JoinUs4Health consortium

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Appendix 1: OECD basic statistics

Table 10. Basic statistics of the OECD economic surveys for Germany, The Netherlands and Poland in comparison to the OECD average [a].

OECD statistics	OECD average	Countries DE	NL	PL
LAND, PEOPLE AND ELECTORAL CYCLE				
Population (million, 2021)		**83.2**	17.5	37.7
… under 15 (%, 2021)	17.4	**13.9**	15.5	15.4
… over 65 (%, 2021)	17.7	**22.2**	20	18.8
International migrant stock (% of population, 2019)	13.2	**15.7**	13.4	1.7
Latest 5-year average growth (%)	0.5	0.2	0.6	**-0.1**
Population density per km² (2021)	38.7	238.1	520.7	**123.3**
Life expectancy at birth (years, 2020)	79.0	80.9	81.5	76.6
… Men	76.2	78.6	79.9	**72.6**
… Women	82.0	83.4	83.1	**80.8**
Latest general election		09/21 [2]	11/23 [2] [03/21]	10/23 [2] [10/19]
ECONOMY				
Gross domestic product in current prices (billion USD)		4067	991	680
Latest 5-year average real growth (%)	1.6	**0.5**	1.9	4
Per capita (thousand USD PPP, 2021)	50.8	58.6	63.3	**38.1**
Value added shares (%, 2021)				
Agriculture, forestry and fishing	2.6	0.9	1.7	**2.6**
Industry including construction	26.6	29.6	20.3	**32**
Services	70.8	69.5	78	**65.4**
GENERAL GOVERNMENT				
Per cent of GDP				
… Expenditure (OECD: 2021)	46.3	49.8	44.5	44.2
… Revenue (OECD: 2021)	38.7	47.1	44.5	42.4
… Gross financial debt (2021)	111.8	77.6	54.7	68.2
… Net financial debt (2021)	70.6	30.7	25.6	37.6
LABOUR MARKET, SKILLS AND INNOVATION				
Employment rate (aged 15 and over, %)	57.5	59.6	65.5	55.3
… Men	65.4	64.6	70	**63.5**
… Women	50.2	54.7	61.1	**47.8**
Participation rate (aged 15 and over, %, 2021)	60.3	60.6	67.9	**57.2**
Average hours worked per year (OECD: 2021)	1727	1341	1427	1830
Unemployment rate, Labour Force Survey (aged 15 and over, %)	5	3	3.5	3.4
Youth (aged 15-24, %)	10.9	**5.9**	7.6	11.9
Long-term unemployed (1 year and over, %, 2021)	1.7	**1.2**	0.7	0.9
Tertiary educational attainment (aged 25-64, %, 2021)	39.9	**31.1**	43.1	33.2
Gross domestic expenditure on R&D (% of GDP, 2021)	3	3.1	2.3	**1.4**
ENVIRONMENT				
Total primary energy supply per capita (toe, 2021)	3.8	3.5	**4**	2.9
Renewables (%, 2021)	11.6	15.6	**10.6**	11.8
Exposure to air pollution (more than 10 µg/m³ of PM 2.5, % of population, 2019)	61.7	86.8	98.6	**100**
CO_2 emissions from fuel combustion per capita (tonnes, 2021)	7.9	7.5	**7.8**	7.7
Water abstractions per capita (1 000 m³, 2019)	na	0.2	**0.5**	0.2

OECD statistics	OECD average	Countries		
		DE	NL	PL
Municipal waste per capita (tonnes, 2021, OECD: 2020)	0.5	**0.6**	0.5	0.3
SOCIETY				
Income inequality (Gini coefficient, 2019, OECD: latest available)	0.315	0.296	**0.297**	0.281
Relative poverty rate (%, 2019, OECD: 2018)	11.7	**10.9**	8.5	9.8
Median disposable household income (thousand USD PPP, 2019, OECD: 2018)	25.5	32.1	34.8	**19.1**
Public and private spending (% of GDP)				
Health care (2021, OECD: 2020)	9.7	12.8	11.2	**6.6**
Pensions (2019)	9.5	10.4	**5.9**	11
Education (% of GNI, 2020)	4.4	**4.4**	4.7	**4.4**
Education outcomes (PISA score, 2018)				
… Reading	485	498	**485**	512
… Mathematics	487	**500**	519	516
… Science	487	**503**	**503**	511
Share of women in parliament (%, 2021)	32.4	34.9	40.7	**28.3**
Net official development assistance (% of GNI, 2017)	0.4	**0.7**	0.6	0.1

na: not available

[a] For selected parameters, statistics are also provided for the regions, where the three population-based cohort projects are situated in, i.e. DE: SHIP: Study of Health in Pomerania in Mecklenburg-Pomerania in Northeast Germany; NL: RS: Rotterdam Study in The Netherlands; PL: PLUS: Białystok PLUS in Poland.

Appendix 2: Overview of platform topics and suggestions

Table 11. Number of followers, contributors, voters and comments as well as status and visibility of topics posted on the JoinUs4Health platform as of 15.12.23 sorted by date in descending orderDetails of topics are shown as table in the JoinUs4Health Deliverable 7.5

No.	Date created	Title	Original language	Followers	Contributors	Votes	Comments	Status	Visibility
1	24.10.2023	Mental health prevention for young people	Polish	1	4	4	0	active	public
2	10.09.2023	Public Health Topic: Strengthening the sun protection competence of the population	German	1	2	6	1	active	public
3	10.09.2023	Public Health topic: Strengthening the mental health of children and young people	German	1	1	5	2	active	public
4	07.09.2023	Public Health topic: Climate change and health	German	1	1	6	0	active	public
5	23.08.2023	Proposals from animal owners in SHIP-One Health	German	0	0	3	0	active	public
6	12.06.2023	Diabetes and pre-diabetes - call for preventive action	Polish	0	0	3	0	none	public
7	15.05.2023	Use of population-based health research in the context of public health	German	0	0	4	0	active	public
8	15.05.2023	Healthy Studying - Healthy University of Greifswald	German	1	0	4	0	continuous	public
9	12.04.2023	Fit at older age	German	1	0	4	0	active	public
10	12.04.2023	DDR Psych Study	German	1	2	4	0	active	public
11	29.06.2022	Sedentary lifestyles - the invisible pandemic of the 21st century	Polish	5	7	8	1	active	public
12	20.06.2022	Multimorbidity: bad luck, coincidence or cause?	Dutch	0	1	3	0	active	private
13	31.05.2022	Gardening for Health: A community garden as a community support to strengthen the recovery of people experiencing a mental health crisis	Polish	4	6	10	9	active	public
14	20.04.2022	Forest bathing	Polish	3	3	6	1	active	public
15	12.04.2022	Festival of The New European Bauhaus	English	1	1	5	2	closed	public
16	11.04.2022	JoinUs4Health related activities	English	2	1	4	0	continuous	public
17	11.04.2022	NEXT-One Health module in the "Study of Health in Pomerania" (SHIP)	German	1	1	5	0	closed	public

Appendix 2: Extract from the Description of Action

Table 12. Specifications of MoRRI indicators which are envisaged to be addressed based on the JoinUs4Health Description of Action

ID	Description
PE	**Public engagement**
PE3	Citizen preferences for active participation in S&T decision making / assessments of working packages
PE5	Generating means and providing resources (cohort results, staff time) to support low- and high-level interactions as part of the platform
PE6	Dedicated resources for Public Engagement / platform, cohort data, educational materials etc.
PE7	Public engagement activities are directly and indirectly embedded in the funding structure of the cohort and associated institutions relating to activities about a) disseminating research to citizens or societal stakeholders, b) involving citizens or societal stakeholders in research activities and c) on public engagement.
PE7	Promotion of RRI activities within the organization by encouraging staff to contribute to working groups is an indirect investment, and this will be sustained after the end of the project.
PE7	Generation and translation of educational materials as well as staff time paid via the project is not fully budgeted so that in-kind contributions by all research partners are envisaged.
PE7	Uptake of citizens' ideas and suggestions into cohort research and assessment of the effects of engagement via questionnaires are covered via non-project funds.
PE7	Performance-based incentives (e.g. annual pot of 10,000 Euros to be distributed to the most active institutions / researchers) are envisaged but cannot be guaranteed without prior in-depth consultations with the university's management body, especially in times of coronavirus. But this indicator will be promoted and evaluated as part of the project.
PE8	One citizen science board per cohort institution, which revises working group proposals
PE8	Encouraging scientific staff to present their ideas to platform users before submitting data access applications and funding proposal
PE9	R&I democratization index / democratic and transparent engagement
ETH	**Ethics**
E1	Ethics at the level of Universities / recognition of contribution, pyramid system - upgrade in experience levels, ethics advisors from various groups of stakeholders)
GOV	**Governance**
GOV2	Establish processes for managing RRI-related governance mechanisms in terms of ethics, citizen engagement, open access and open science, gender equality, responsible research and innovation and formal, informal and non-formal science education in various ways
GOV3	Encourage researchers to address these fields
GOV3	Encourage other institutions to address these fields.
SLSE	**Learning and education**
SLSE2	RRI related training / e.g. training of researchers and PhD students)
SLSE3	Science communication / targeted communications and disseminations
SLSE4	Citizen science activities in RPOs / measured by number of platform users and working groups

ID	Description
GE	**Gender equality**
GE10	Number and share of female inventors and authors
OA	**Open access**
OA3	Social media outreach
OA6	RPO support structures for researchers / incentives for data sharing, RRI training and engagement via the platform and other means).

Appendix 3: Details of the process evaluation using the NEOH tool

Appendix 3.1: Details on the assessments

Thinking (11 questions): Refers to the way actors and stakeholders think within and about the system and the initiative. It assesses how the dimensions and scales under consideration (e.g., local, regional or global scales within geographical space; timeframe of the initiative; life; network or organization; economy; legislation; governance; and value constructs such as interest groups) may support or limit the outcomes and impacts of the initiative.

Planning (12 questions): Requires that aims, problem formulation, responsibilities, resource allocation and financing of the initiative are systematically organized. It also requires clarity in establishing roles, tasks, responsibilities, and competencies of participants.

Working (10 questions): Explores the extent to which engagement in the initiative was interdisciplinary and participatory (i.e., transdisciplinary). The establishment of non-hierarchical relationships, strategic dialogue, and shared decision-making between team members coming from different disciplines promote transdisciplinarity.

Sharing (10 questions): Refers to the information and data-sharing infrastructures in the initiatives including internal or external mechanisms used for sharing information, allocation of resources to facilitate and ensure data sharing and mechanisms for safeguarding access to data.

Learning (13 questions): Covers learning style (i.e., whether basic, adaptive or generative) and setting (i.e., at the individual, team and organizational level) as well as the type of environment, i.e. stakeholders involved ("direct" environment), and the cultural, economic, and political situation surrounding the initiative ("general" environment).

Systemic Organization (17 questions): Assesses to what extent the initiative was facilitated by change-oriented leadership and effective teamwork. This also indicates how closely it is related to and influenced by Planning.

Appendix 3.2: Reflections on and interpretations of the results

A3.2.1: Thinking

Overall score: 0.74

Eight different dimensions were considered: Space, Time, Engagement, Open Access, Education, Ethics, Gender, and Governance.

The three-year funding period allowed implementing the design and early implementation stages. The reflections on the conceptualization continued during the first two years, and we had to adjust our planned approaches over time as we have not yet been able to generate sustained Team interactions via the platform. However, the initiative has a highly integrated approach, covering diverse dimensions at differing scales and incorporating many perspectives. A range of activities were implemented in all three countries, which provide valuable lessons for learning and are documented in more detail in D7.5. Furthermore, the initiative has potential impact in various areas (science, society, …; see Section 0), but this cannot yet be captured at this stage. The knowledge generated via the initiative provides learning opportunities also for the international community.

A3.2.2: Planning

Overall score: 0.6

Target groups and their characteristics were described in the Communication and Dissemination strategy (D6.4). But given the slow progress in building an active community (locally or online via the platform), engagement has been slower than expected and community building remains an ongoing task. Given that the concept and platform can continue to be promoted, there is potential to achieve a sustainable shift in mind set amongst scientists and the local societies.

The engaging scientists, regional partners, advisory board members, participants in offline activities and platform users provide a diverse interest group in this initiative, many of whom are keen and willing to promote the initiative further. The formal and informal education and communication materials and informal networks generated provide potential to achieve the expected outcomes over time. Regular biweekly reflections amongst partners allowed responding to change in circumstances. But feedback from stakeholders and advisory groups could have been incorporated more systematically. Also matching of roles, responsibilities, and competencies could have been improved.

The median score for RRI planning (0.60) was calculated considering the extent to which resource allocation matches the planned tasks and responsibilities.

Furthermore, the lack of prior experience in RRI of cohort partners caused considerable delays early on due differences in perspectives. Therefore, WP2 staff had to invest a lot of time in revising deliverables and mentoring cohort partners in taking on the RRI mindset. On the other hand, at times for cohort partners a strict RRI philosophy appeared impractical and at times counterproductive to the overall ambition of the project.

Considerable support was given at all three cohort institutions by staff not paid through the project. Although this can be partly seen as being in line with institutional changes, it created

a lot of pressure and impeded efficient implementation at times. RRI is about slowing down. We have not been able to achieve that during the course of the project.

Social scientists (UwB) engaged with the Białystok group, but not very much with the Greifswald and Rotterdam groups.

Cohorts are well-respected in the scientific community. The project aimed to demonstrate the value these cohorts bring more also to the local societies.

We aimed to apply a bottom-up approach. But cohorts can also provide value by sharing information … → Discuss in D7.5

Interaction with volunteering platform contributors was strongly supported by project staff members. No substantial team interaction emerged via the platform. Offline events in Białystok however created considerable offline event.

The project also aimed to build an intersectoral network.--> overall successful

A3.2.3: Working

Overall score: 0.8

The partners brought different experiences and perspectives into the project. Regular exchanges were overall fruitful in developing an open and overall trusting relationship. The time pressure however caused tensions as the preparation of deliverables often started late providing little option for input or causing delays due to in-depth revisions of the final draft. Further details can be found in D7.4. Furthermore, the third year showed an increase retreat of partners given their high work load and need to focus on their own activities.

The project is broad and targets a diverse set of societal groups. We managed to specifically target the following societal groups: Youth (all cohort regions), public health authorities (SHIP), NGOs and business representatives (Bialystok PLUS) as well as senior citizens (SHIP).

At each occasion we presented the methodology and discussed it with participating actors, allowing us to adjust and fine-tune our communication of the concept over time. The image film is one important output promoting a better understanding of the concept in a short time.

The three cohort partners (UMG, MUB and EMC) were most similar given their medical and academic background. Our mentoring partner (EUR) brought it the philosophical perspective, which at times was in contrast to perspectives by the cohort partners. Furthermore, we had an academic partner with background in social sciences, 3 NGO partners, one marketing and one IT company as well as one partner working closely with public health authorities.

Even within cohorts, different disciplines are involved such as epidemiology, clinical medicine and laboratory diagnostics with different specialties working closely together in order to allow the in-depth examinations of cohort research. But the aim was most of all to reach out beyond academia and the medical field.

In terms of the concept, the JoinUs4Health project was open and flexible. The only restriction was that a link to human health needs to be present. However, some key assumptions were not met, which caused much higher efforts required for dissemination, outreach and engagement. This was further exaggerated by problems in recruiting and retaining staff, especially at UMG. The problems in relation to low staff resources are outlined further in D7.4.

Another shortcoming was that there was an imbalance of actors. Although the project was open to everyone from the age of 16 years and a large number of people were informed about the project, the offer to engage does not appeal to everyone. Therefore, rather than collating suggestions and mobilising volunteers from a broad range of society and complementing this via targeted outreach activities to minority groups, we encountered a low level of interest in the majority and a vested immediate interest from individuals. Hence, purely relying on suggestions via bottom-up approaches without any cohort input may result in topics being promoted that are neither representative of the population nor supporting the needs of underprivileged groups.

Also some methodological shortcomings were encountered. EUR was the only partner with experience not just in RRI, but also in co-creation and systems thinking methods. In hindsight, we should have placed more emphasis on including time for co-creation and systems thinking to allow targeted engagement of stakeholders already at the planning phase.

We found it difficult to explain the RRI methodology in brief. Following advice from the international RRI panel, we did not specifically frame the concept around RRI when communicating with non-academic target groups. But even within the cohort institutions, the RRI concept was not clear for an extended period of time. This caused difficulties in implementing the methodology and is likely to cause difficulties also when communicating the concept and potential value to decision-making bodies. A stronger emphasis on risk management, could have allowed to adapt more swiftly and more systematically to internal and external challenges we experienced.

A3.2.4: Sharing

Overall score: 0.6

The project has created new mechanisms to allow sharing of information, i.e. website, platform, social media channels. There was no regular written reporting other than project outputs and meeting reports. Also feedback on workshops and activities could not readily be shared with partners due to time constraints. No face-to-face meetings were budgeted, which may have contributed to the long time required to achieve similar understandings and visions of the project.

No peer-reviewed publication has been achieved yet, but seven manuscripts have been prepared or are in preparation. Details of manuscripts that were rejected or withdrawn are provided in D7.5. Compliance with confidentiality and data protection issues need to be tackled since it may interfere with data sharing and accessibility. It would be valuable to discuss methods and results with partners once more in light of all available project deliverables and in preparation for the final project report.

A3.2.5: Learning

Overall score: 0.5

Mutual learning and mentoring are key organizational features embedded in the design of the JoinUs4Health project. Given strained human resources, mutual learning between partners took place at a lower level than we hoped for. Each group generated a range of outputs and carried out activities. But materials and lessons learnt could not be adequately be absorbed by

the other partners due to the relentless time pressure and the passion to invest as much as possible in the own cohort region.

Biweekly team meetings (1 hour) provided space for all partners to share and reflect on experience, thus allowing joint decision-making and corrective approaches. One-hour meetings are however too short to engage with partners on topics in-depth. Furthermore, the structure and documentation of the biweekly meetings was inconsistent due to staff turnover at UMG.

The experiences we made and documented in D7.4 and D7.5 provide valuable insights into how to improve procedures and promote Responsible Research and Innovation in different settings / with different approaches. Challenges include that RRI remains an elusive concept, making it difficult to communicate to scientists and citizens alike. Furthermore, the lack of institutional incentives creates a real barrier for meaningful engagement of scientists as long as there is no clear support from the top-level. Hence, to achieve a true shift towards RRI, a mind set needs to take place amongst scientists coupled with an incentive system, which does not disadvantage scientists open to engage with societal stakeholders.

Mutual learning was expected to take place between cohort regions, recognizing that the three cohort regions in Bialystok (Poland), Mecklenburg-Pomerania (Germany) and Rotterdam (The Netherlands) differ considerably in various aspects (e.g. level of awareness of the cohorts in the region, socio-economic factors, internet access, …). Furthermore, the third year was designed to exchange experiences between Work Packages to facilitate implementation in the other cohort regions. Mentoring was included in the project design as none of the partners other than EUR had prior experience with RRI.

JoinUs4Heatlh aims to involve different societal groups, e.g. citizens, public health authorities, students and pupils, etc. (see D6.4). A shift in mind set is also required at the societal level. People are not used to engage with science or work together with people from different backgrounds on a defined topic. As the concept continues to be implemented, the brand JoinUs4Health may be increasingly recognized, thus contributing in turn to a shift in societal mind set.

A3.2.6: Systemic organisation

Overall score: 0.7

In JoinUs4Health, team work is key, not just between partners, but also within institutions and, as per design of the crowdsourcing methodology, also between science and society. Teams on the platform are ideally comprised of people with a diverse set of backgrounds. Therefore, team work is required at different organizational and operational levels. Due to the RRI-ambition, inter- and transdisciplinary approaches are encouraged. But this is not yet done in a systematic manner, and no guidelines have been provided yet as to how future moderators should promote inter- and transdisciplinarity.

The Working Packages are highly interrelated and interdependent, each aiming to involve people from different target groups. This has caused challenges when a Work Package output relied on the work of other Work Packages, which have not yet completed or reported on their activities.

Task-oriented, relationship-oriented, and change-oriented leaderships were present, but not clearly balanced. Regular online meetings took place, but discussions were at times circulating

around topics, for which no clear conclusions could be formulated. Further systems thinking workshops and face-to-face meetings may have helped achieving a consensus.

The JoinUs4Health project operates in complex settings as it

- Brings together 11 partners from three different member states
  - with only one partner experiences with RRI
  - with a range of backgrounds
- is expected to
  - change the traditional way science is conducted in cohort institutions, which are rather conservative in their approach compared to other disciplines, and
  - overcome intrinsic barriers within the institutions (e.g. time pressure and conflicting demands, little prior RRI knowledge, …)
  - engage local societies in two cohort regions that can be regarded as low-… (see Section 0).

Therefore, this project requires different types of leadership:

- task-oriented with the aim is to accomplish work in an efficient and reliable way
- relationship-oriented with the aim to increase the quality of human resources and relations, which is sometimes called "human capital"
- change-oriented with the aim to increase innovation, collective learning, and adaptation to the external environment

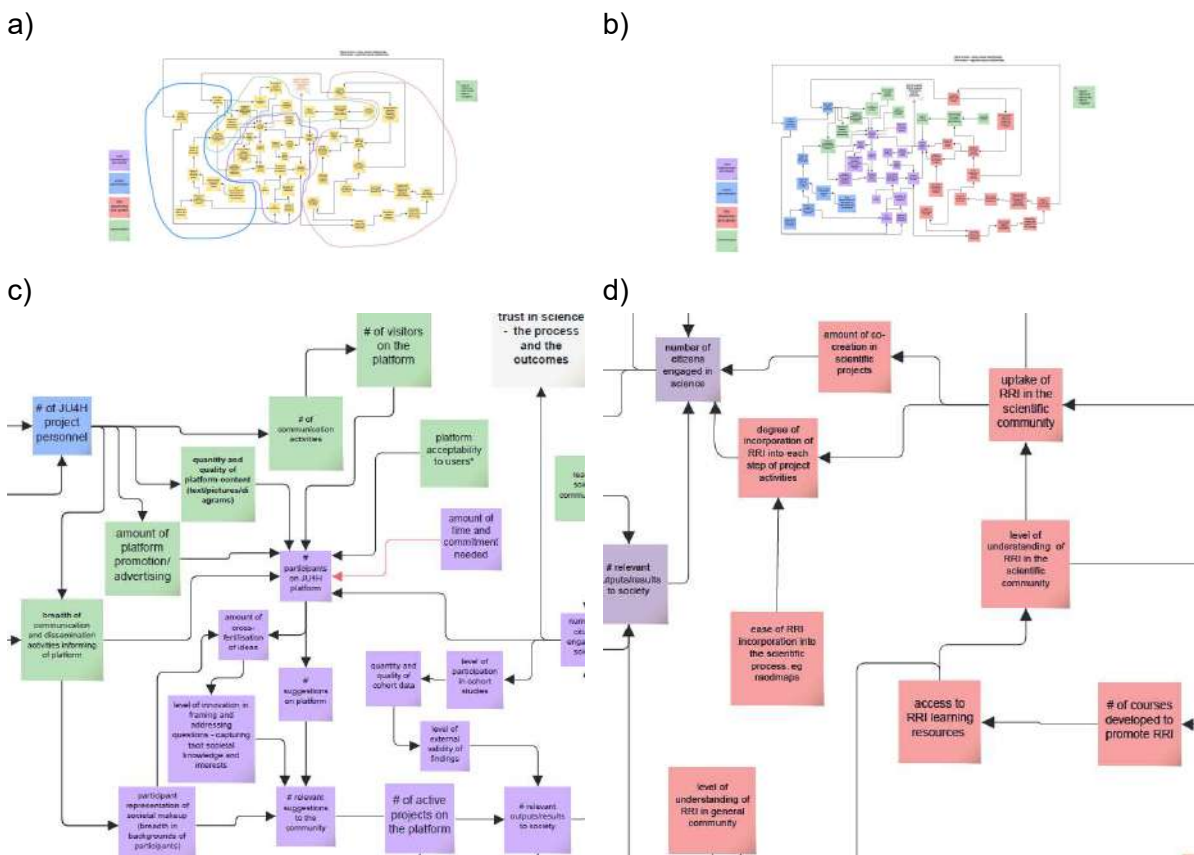## Appendix 4: Systems map

a)

b)

c)

d)

Figure 12. Development of systems maps (a: grouping, b: colour-shaded) and extract from the colour shaded systems map generated during two workshops in 06/21 with Simon

Rüegg (University of Zürich) and partners and in 03/22 with Johanna Dups-Bergmann (scientist from the Friedrich-Loeffler-Institut, Riems, Germany) and partners.

Black arrows = same causal relationships

Red arrows = opposite causal relationships

Colours of the boxes: purple: JU4H implementation and impacts, blue: project administration, red: RRI awareness and uptake, green: Communication

Appendix 5: MICS impact evaluation report

Society / Activeness	The activeness of participants within a project is an important aspect of citizen science, and this project has made great efforts to ensure participants are aware they are contributing to a research project, have responsibility in the project, and are satisfied with the process of participation. Great job!	
Governance / Policy	It looks like policy influence might not be a priority for the project. Of course, not every project can affect policy and some projects have a large impact on governance without ever interacting with official policy. If you're interested in the idea of citizen science as a form of socio-technical governance you can read more in this paper. If the project is interested in influencing policy it could find inspiration from example projects in this report. It might not be a viable option if the project has already started, but citizen-science projects most often have success influencing policy when specific policies are considered in the design of the project and policy makers are engaged from the start of the project.	
Economy / Economic productivity	It is great that the project has produced outputs that contribute to the economy through industry, commerce, innovation or technological development. If you haven't already, it might be worth considering any legal implications through a dedicated IPR plan.	
Economy / Financial sustainability	You are on the right path! It is clear that the project has considered its financial sustainability into the future. However, there could be more to do. If one does not already exist, an exploitation plan could help sustain project outputs, whilst considering open-source software and tools could reduce costs.	
Environment / Environmental footprint	This indicator considers the project's material footprint, polluting emissions, procurement policy, and pro-environmental actions for participants (such as litter picking). The project's score for this indicator shows that the project has considered some of these elements but to get a higher score the project needs to take measures to improve its environmental footprint in all these areas.	
Environment / Environmental awareness	The project clearly promotes environmental awareness, by educating participants on environmental challenges, or by contributing to participants' awareness of the natural environment through dissemination activities. Want to be able to measure participants' higher awareness, or increased stewardship? You might want to consider this paper.	
Science / Interdiscplinary science	By working across multiple disciplines, this project is making efforts to promote interdisciplinary ways of working. There is evidence that interdisciplinarity is statistically significantly and positively associated with research impact (Okamura, 2019), largely through the engagement of a wider audience. Keep up the good work!	

Figure 13. Results of the impact evaluation report using the MICS tool[25]

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[25] https://mics.tools/projects/joinus4health

Terminology

Most definitions were based on the guidance document "Horizon 2020 indicators: Assessing the results and impact of Horizon 2020".

Baseline	a) in relation to cohort research: baseline examination means the first examination of a cohort participant; b) in relation to indicators: the value of the indicator before the JoinUs4Health project has been undertaken, i.e. the situation within the local societies of the cohort study regions and beyond before the JoinUs4Health intervention
Common indicators	a list of indicators with agreed definitions and measurement units to be used where relevant, permitting aggregation to the national and EU level
CORDIS	Community Research and Development Information Service for Science
Evaluation	An evidence-based judgement of the extent to which an intervention has: (i) been effective and efficient (ii) been relevant given the needs and its objectives (iii) been coherent both internally and with other EU policy interventions (iv) achieved EU added-value
Impact	The wider societal, economic or environmental cumulative changes over a longer period of time
Impact indicator	What the successful outcome should be in terms of impact on the economy/society beyond those directly affected by the intervention
Indicator	The measurement of an objective to be met, a resource mobilised, an effect obtained a gauge of quality or a context variable. An indicator should be made up by a definition, a value and a measurement unit
Input	A material, human and/or financial resource directly used in the implementation of a policy intervention
Method	families of evaluation techniques and tools that fulfil different purposes. They usually consist of procedures and protocols that ensure systemisation and consistency in the way evaluations are undertaken. Methods may focus on the collection or analysis of information and data; may be quantitative or qualitative; and may attempt to describe, explain, predict or inform action. The choice of methods follows from the nature of the intervention, the evaluation questions being asked and the mode of enquiry – causal, exploratory, normative etc. (European Commission 2014)
Monitoring	observe whether intended products are delivered and whether implementation is on track

Output	Outputs are what is **directly produced or supplied** through the EU intervention. They often relate to the expected deliverables of the intervention. Outputs generally occur within the short to medium term
Outcome	The **direct, and usually observable, effect of a policy intervention** on its target population, which is consistent with the policy intervention goals, and would not have occurred without the policy intervention
Output	direct product of a programme intended to contribute to results
Output indicator	an indicator describing the "physical" product of spending resources through policy interventions. Examples are: the length, width or quality of the roads built; the number of hours of extra-teaching hours provided by the intervention; the capital investment made by using subsidies. or the specific deliverables of the intervention
Result	Captures more direct, short to medium term changes in a situation.
Result indicators	Represent the immediate effects of the measure concerned and look at its direct addressees