Join Us to Optimize Health Through Cohort Research

Deliverable 3.1 Report on the technical requirement including tools to be used for webinars

Part I: Concept and process

Version 1.0

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List of abbreviations

AkademieÖGW	Akademie für Öffentliches Gesundheitswesen in Düsseldorf, Germany
EUR	Erasmus University of Rotterdam, Netherlands
EMC	Erasmus Medical Centre, Rotterdam, Netherlands
GDPR	General Data Protection Regulation
MUB	Medical University of Bialystok, Poland
OH	One Health
P	Partner
RRI	Responsible Research and Innovation
SocLab	Foundation Laboratory of Research and Social Actions "SocLab", Bialystok University of Technology, Poland
UMG	University Medicine Greifswald, Germany
UwB	Social Science Department, University of Bialystok, Poland

1 About Part I of this deliverable – Concept and process

This document describes our current thinking regarding the concept and processes to be applied as part of JoinUs4Health. The concept and procedures in turn form the basis to specify technical requirements (see part II from page 39 onwards) for the platform, which is due to be publicly accessible in December 2021. We will gather feedback from representatives of the five groups defined as part of the Responsible Research and Innovation (RRI) framework (scientists, citizens, policy makers, education community and business / industry).

2 The JoinUs4Health project

2.1 Overview

Key take aways:
JoinUs4Health combines RRI and crowdsourcing approaches to promote innovation, engagement and easier access to science.   We believe that   • cohort research has a lot to offer to society and   • society and particularly the interaction between individuals from different backgrounds, societal strata, societal groups, sectors and disciplines has a lot to offer to science

Aim: We want to combine RRI and crowdsourcing as converging approaches to promote inclusive innovation and citizen engagement in cohort research.

Ambition: We want to make cohort research more sensitive to societal expectations and concerns and to promote equal access to science, especially in the field of health and life sciences by engaging 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.

Project objectives / work packages are shown in Figure 1 and described in Annex I.

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

Our offering: Semi-open access to cohort results from three EU Member States (Germany, the Netherlands and Poland). See Annex II.1 for further details on the three participating cohorts.

Hypotheses: The proposed approach has the potential to
- increase citizens' science skills and interest in science,
- enrich cohort research by tapping into the collective intelligence of the community (questions, needs, concerns, insights, experiences etc.),
- create spaces for reflection on RRI and equip people to engage in such reflections, and
- counteract the decreasing preparedness of citizens to participate in medical examinations of cohort research.

Key requirements: Long-term sustainability and transferability to other institutions and regions are key requirements when designing the concept, platform and procedures.
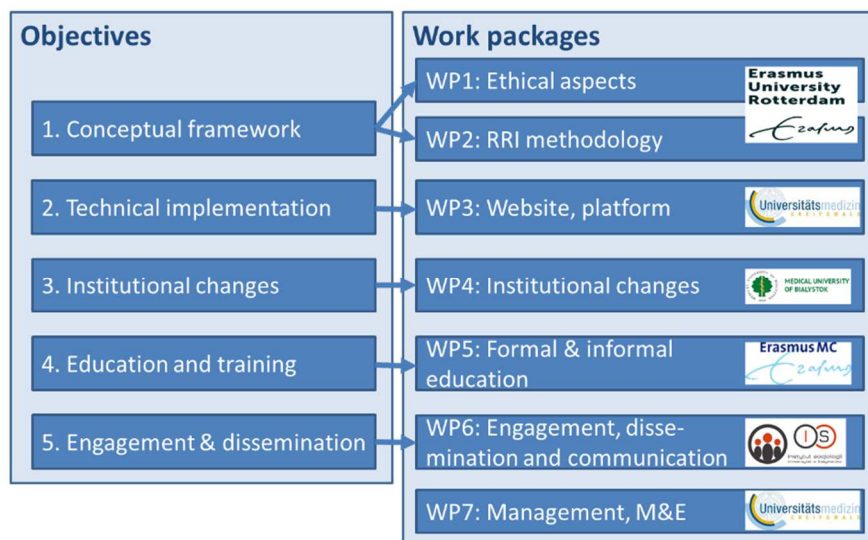
Figure 1. Objectives and work packages (WP) of JoinUs4Health. Further details can be found on the project website[1]. Work package leaders are Erasmus University of Rotterdam (EUR; WP1 and WP2), University Medicine Greifswald (UMG; WP3 and WP7), Medical University Bialiystok (MUB), Erasmus Medical Center (EMC) and University of Bialystok (UwB).

2.2 Project phases

Key take aways:
- this document forms an important step in the process of project implementation   - feedback collated based on this document will be integrated in the Deliverable 3.1 (due on 30/06/2021), based on which a platform prototype (31/08/2021) will be developed and refined until the platform is fully released in 31/12/2021

The JoinUs4Health project received funding for a three-year period (01/2021 – 12/2023), which can be divided into four phases (conceptualization, design, implementation and transfer / transition). The design phase can be split into sub-phase I and II based on the availability of a platform prototype.

Conceptualization
01/2021-04/2021
- Review concept
- Communication & dissemination
- Website

Design phase I
05/2021-07/2021
Revise design concept, guidelines, …

Design phase II
08/2021-11/2021
Test of platform and concept with first volunteers

Implementation
12/2021-11/2011
Still considerable input through project staff and associates

Transfer and transition
12/2022-12/2023
- Transfer approaches between cohorts
- Increasing reliance on JoinUs4Health "community"

Figure 2. Phases of the JoinUs4Health project

2.3 Concept

<table>
<tr><td>Key take aways:</td></tr>
<tr><td>

- the JoinUs4Health crowdsourcing concept is multi-directional as there is no single crowdsourcer, but any community member can act as crowdsourcer or contributor
- uptake of suggestions depends on the interest of the community and strategic promotion of key topics
- the main beneficiary of the produced outputs is society
</td></tr>
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The crowdsourcing approach of JoinUs4Health was initially proposed to bridge the gap between science and public health (Schauer, 2018), but is in principle applicable to any research field. Traditionally, crowdsourcing includes four elements (Brabham, 2013):

- an individual or an organization has a task (questioner),
- a community addresses the task (crowd),
- a platform enables the task to be addressed and crowd members to interact,
- a benefit arises for both the questioner and the crowd.

Note: In the crowdsourcing literature, the questioner and crowd members are also referred to as crowdsourcer and crowdsource or contributor. We use the terms crowdsourcer and contributor. See further details on crowdsourcing and RRI in Annex II.2.

A key adjustment to the traditional crowdsourcing approach is that any individual of the crowd may either act as crowdsourcer (questioner) or contributor (crowd member). Instead of an individual or organization <u>obtaining</u> input from the crowd (uni-directional), the JoinUs4Health community becomes the driving force in all dimensions of the crowdsourcing process making suggestions, deciding which suggestions are followed, engaging in implementation, review, evaluation, dissemination and decision-making. This community-driven, multi-directional approach is further promoted by the targeted engagement of different societal groups, disciplines and sectors.

The crowdsourcing concept is multi-directional in the sense that

- there is no single crowdsourcer, but any community member may act as crowdsourcer and crowdsource,
- the three partner cohorts can crowdsource within cohorts and then between cohorts, and
- teams can build upon work of previous teams and inform other teams.

The main beneficiary is society rather than a single organization. The goal of the platform is to optimize benefits for society. Volunteering contributors (from any RRI group) shall increasingly gain knowledge and experiences and take over system-relevant tasks. The main incentive for the individual is the perceived contribution to society.

The concept includes low- and high-level interactions, targeted delivery of knowledge relevant to society and formal and informal education opportunities (Figure 3).

Low-level interactions (1-3) include the steps

- SUGGEST (1),
- VOTE (2) and
- SELECT (3).

High-level interactions via facilitated teams (4) consist of

- IMPLEMENT (4); either
  - PLAN (4a) and IMPLEMENT (4b) facilitated teams and PRESENT (4c) / DISCUSS interim results (4d) or

- IMPLEMENT as individual (4b) and present for review (4c/4d); in some cases the individual proposes a plan first (4A)
  - option to APPLY for cohort results (4e)
- Submit outputs for REVIEW
- DISSEMINATE via the platform and website as well as social media (5).

This concept provides the option to apply for access to SCIENTIFIC RESULTS (4b). Criteria to determine when an item transits from one stage or level to another are outlined in Annex II.
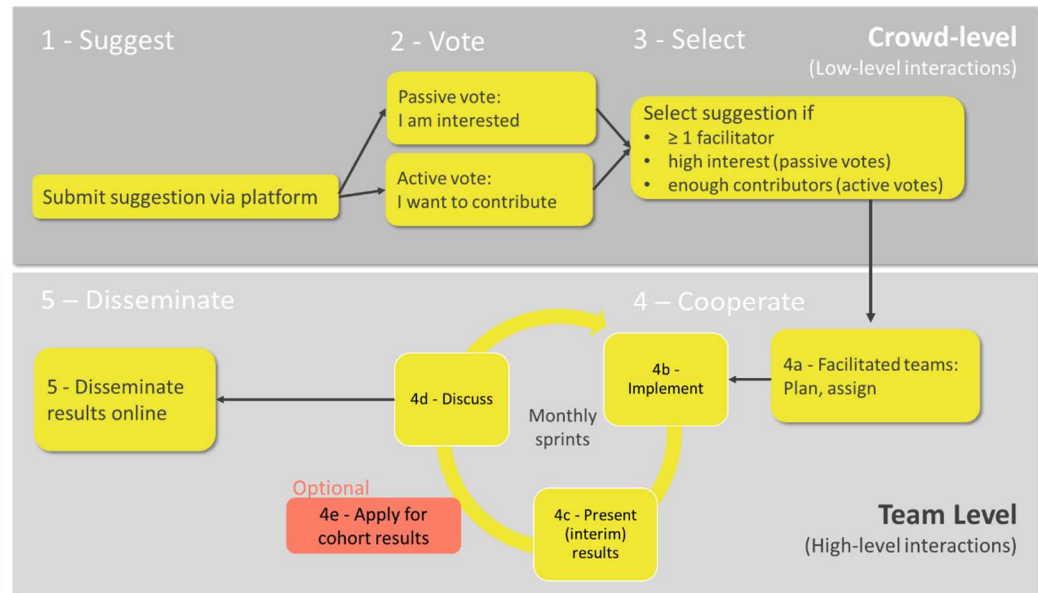
Figure 3. Core mechanism of JoinUs4Health with five core steps.

3   JoinUs4Health framework conditions

Crowdsourcing is a system or concept (depending on which aspect is rather emphasized), comprised of framework conditions and elements or components (!!! INVALID CITATION !!! (Pedersen, Kocsis et al. 2013, Wedel and Ulbrich 2021)). We chose a systematization approach recently published by Wedel and Ulbrich (2021), which differentiates between

- three framework conditions (external, internal, and strategy; section 0) and
- three crowdsourcing components, i.e. process, activity and information technology (see section 4).

Responsible Research and Innovation approaches and methods[2] as well as drivers and barriers (Wittrock et al., 2021) are important to consider at all stages (e.g. match individual from different groups, promote diversity, disseminate to targeted groups, …).
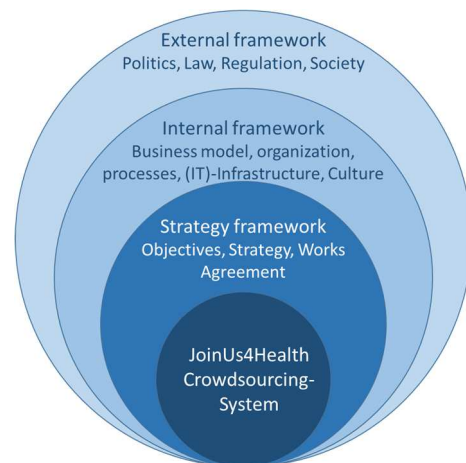
Figure 4. Framework conditions for crowdsourcing. Adapted from Wedel and Ulbrich (2021)

3.1 External framework conditions

3.1.1 Societal challenges of our times

COVID-19 has had a huge societal, mental and physical health impact, the extent of and potential solution for which need to be jointly explored. The shake-up of our societies emphasized the need for joint reflection, mutual learning and knowledge exchange. The COVID-19 pandemic has also shown that coercive action can become an important factor in determining a society's response to an acute challenge. Due to the long-term impact the COVID-19 pandemic will have on educational training, the online format of JoinUs4Health can serve as proof-of-principle for other educational institutions to adapt their curricula, methods and approaches. Most of all, all three cohorts collect data on COVID-19 diagnostics, vaccinations and related data. Hence, these data could become part of the mutual exchange and a stepping stone towards joint solutions. Trust and co-creation may help us to establish stronger resilience against such challenges.

3.1.2 EU Research and Innovation funding programme 2021-2027

Strategic planning will be a key element to make JoinUs4Health a long-term success by aligning societal and individuals' needs and expectations raised via the platform with activities and strategies at the local, national and European level. The EU's strategic plan (European Commission, 2021) for the research and innovation funding programme 2021-2027, which is expected in mid-June 2021, defines six clusters[3], which can to some degree be addressed via JoinUs4Health. Thus providing future funding opportunities. Such aspects need to be considered especially under the aspect of sustainably and strategic coercive action.

3.1.3 Decrease in cohort response

Over the last decade, the validity of cohort data is increasingly jeopardized worldwide due to a decline in response, i.e. citizens' preparedness to participate in population-based cohort studies. In SHIP for example baseline response decreased from 68.8% to 50.1% within ten years. Notably, response in established cohort studies is still higher than in newly established studies. Our hypothesis is that a decrease in public interest in science and health research and an increasing scepticism towards science are the true societal challenge underlying the observed decline in response.

If citizens are empowered to influence the scientific process and thus feel more in charge of the effects of research on their life, this is likely to strengthen interest in research and thus participation. Hence, as part of this project the effect of RRI implementation on participation in cohort studies is specifically evaluated as this would create a convincing argument for other research performing organizations to apply such an approach as an enhancing effect on response would be a business argument for other cohort institution to apply a similar approach.

3.2 Internal framework conditions

3.2.1 Organisation / governance

Governance is carried out by means of governance mechanisms (Dahlander et al., 2008). Pedersen et al. (2013) proposed

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[3] Cluster (1): Health – (self-explanatory); (2) Culture, Creativity and Inclusive Society (via social and transformation); (3) Civil Security for Society (via capacity to enhance disaster-resilience of societies regarding pandemics and climate-related health risks; (4) Digital, Industry and Space (via next generation internet approaches); (5) Climate, Energy and Mobility (via climate science and contributions to healthier communities and cities); (6) Food, Bioeconomy, Natural Resources, Agriculture and Environment (via enhancement of food security and environmental awareness; potential link with One Health).

- four governance challenges, i.e. (1) effective task break-down mechanism, (2) effective task integration mechanisms, (3) effective incentive mechanism and (4) effective quality assurance system and
- five governance mechanisms, i.e. (1) Right Incentive Mechanism, (2) Managing Submissions, (3) Loss of Control, (4) Quality of the Ideas, (5) Creating Trust

Blohm et al. (2017) suggested six classes ('Task Definition', 'Task Allocation', 'Quality Assurance', 'Incentives', 'Qualification' and 'Regulation') and 21 governance mechanisms. Based on the systematization by Wedel and Ulbrich (2021), the details of these proposed mechanisms will be reviewed in more depth.

3.2.2 Culture

The following quote illustrates the difference between the terms crowd and community.

> *"There is a difference between a community and a crowd. In a crowd, people push and shove and try to get a step ahead. In a community, people look around, they smile, say hi, share a story, because they know that a community doesn't move forward unless they all move forward together. Social done right can make a great community go forward."*

Doug Ulman, president and CEO of LIVESTRONG[4]

As part of JoinUs4Health, we strive to create a community rather than a crowd. More precisely, we aim to create a "population-based community" with an outreach as far as possible into different strata of society. The motivation to participate may differ. Whilst some community members share the general vision to improve health and happiness of the population of the study regions and beyond, others may contribute to or support JoinUs4Health due to other motivations and reasons (e.g. gamification rewards, social interaction, institutional rewards, …).

The overall JoinUs4Health community can be broken down into sub-communities such as RRI stakeholder groups, geographical region / cohort, age group, gender, activity level as part of the JoinUs4Health platform etc. (see section 0 for further details).

3.3 Strategy framework conditions

Strategic framework conditions include objectives, strategy and work agreement. Project objectives are described in Annex I.1. This section covers "strategic decision-making" (strategy) and "dataprotection and intellectual property" (work agreement).

3.3.1 Strategic decision-making

A key distinction between the JoinUs4Health community and a network, which is generally loose and without oversight, is the establishment of citizen science groups and monitoring and evaluation groups in each of the three cohort study regions comprised of different societal actors. These advisory boards with 60 members (ten members per board per country) will serve as a link between the JoinUs4Health community and cohort institutions including their scientific management board, data protection and ethics officers. Wider community-level decision-making will be promoted, possibly requiring some prior engagement / information (informed voting) rather than being able to "blindly" pick an option.

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[4] https://medium.com/@danielcaeiro/crowd-vs-community-a17137e16051
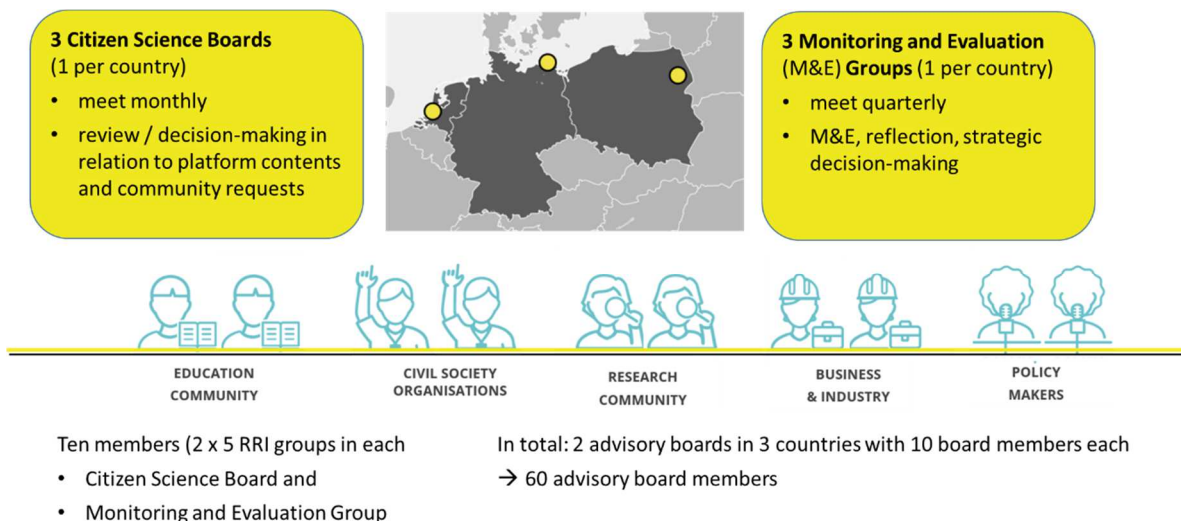
Figure 5. Overview of citizen science boards and monitoring and evaluation groups

3.3.2 Data protection

Multiple external factors may influence the feasibility of the project and affect its potential success. One of the key issues is personal data protection. All partners function in the agreement of all General Data Protection Regulation (GDPR) rules. Health data are a particular type of information that has to be specially protected. Data from cohort studies contain both results of medical examinations and very detailed personal information on family history, addictive behaviour, lifestyle and even income. Therefore the need for protection of such sensitive data is of utmost importance.

Each partner running a cohort study has developed its own policy and standard operating procedures (SOPs), including physical separation between health information and personal data such as name, address, date of birth etc. However opening the datasets to a wider audience may also increase the risk of security breaches. Therefore, partners agreed that all data to be worked on have to be fully anonymized and as a rule citizen scientists will receive them in aggregated form. Only in exceptional situations for experienced individuals who sign an appropriate agreement with the respective cohort institution(s) and work with experienced cohort researchers, pseudonomized data may be provided, but without information that may allow identification of cohort study subjects. The personal data of the participants of this project will be protected based on the GDPR policies.

Details regarding ethics, data protection and intellectual property are specified in the Deliverable "POPD - H - Requirement No. 1".

General requirements

All EU projects processing personal information about identifiable human research subjects are subject to the General Data Protection Regulation (GDPR) ([Anonymous], 2018), which requires data processors to establish and document data protection compliance processes. A GDPR checklist[5] is available for data controllers outside the EU territory.

Data protection by default means that anyone providing personal data has the right to receive clear information about the processing of personal data, i.e. what data are being processed and for what purposes. Key elements are

- data protection by design and by default,
- data minimization,
- risk based approach,
- mandatory Data Protection Officer,
- data protection impact assessments, and

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[55] https://gdpr.eu/checklist/

- accountability based approach.

By default, the only data that should be processed and stored for a limited time is the data which is necessary in order to use the platform and the following rules apply ([Anonymous], 2019):

- data are only accessible by a limited number of authorized persons
- the user can decide whether to make their data publicly accessible
- the user has the right to
  - object
  - access all the data kept about the respective user
  - be informed if data has leaked
  - be forgotten

Data security

- Assure a high standard of security around platform users' personal data needs
- Take into account the risks associated with the data

3.3.3 Ethical issues and intellectual property

Ethical issues and the meaning of the informed consent present other important aspects to consider. There is a wide debate, both academic and legal as to how precise the description of the study goals has to be for a participant to sign an informed consent. All prospective cohort studies that are not focused on one particular hypothesis (such as the ones participating in this project) are run based on the assumption that it is possible to accept an open consent – participants agree on analyses of the data that involve particular aspect, but the hypotheses will be developed in the future.

In the course of this project there may be situations where intellectual property rights (IPR) may be involved, both concerning the research by citizen scientists and algorithms and methods developed for the project. The partners agree that the direct results of the project (platform, information strategy, reports, policies) will be available for the general public as open source. Cohort data that are already available and to be provided for JOINUS4HEALTH research etc. will be still owned by the participating institutions (Background IPR). The results of the research that is fostered by the proposal will be owned by the directly involved scientists and institutions, based on the local policies and agreements (Foreground IPR).

4   JoinUs4Health crowdsourcing components

A simple, yet solid three-component (process, activity, information technology; Wedel and Ulbrich (2021) was chosen to define the JoinUs4Health crowdsourcing system.

4.1   Topic proposal

Any registered user can propose topics, which are initially not yet made public. Two voluntary reviewers from the JoinUs4Health community need to check the submission against defined criteria. If no objections arise, the suggestion is made publicly visible.

4.2   Community management

The process will be organized in fixed monthly sprints from 09/2021 to 11/2023: Every 4th Wednesday of the Month. Initially the project team will oversee the sprints, but input from the community is welcomed and encouraged.

During each sprint, a selection of featured topics is presented via

- website
- newsletter and

- social media.

Aims of sprints:

- focus attention of the public,
- engage public in decision-making,
- plan next month work in terms of
  - Teams
  - Tasks
  - Suggestions
- inform about developments, offers and needs.

Table 1 outlines the proposed design of a typical 30-day sprint. A team can continue to work over several sprints. Every four weeks, team members can leave the team and new members join. This dynamic approach of four-weekly sessions allows
- individuals to engage without an uncertain, long-term commitment
- flexibility in time contributions
- ex-members to stay engaged even after (temporarily) leaving the team
- individuals with little time on hand to provide spot inputs at interim intervals.

The facilitator and team members (ideally jointly) plan a sprint by defining small tasks, which are manageable to implement over a two-week period. Sprint planning and documentation is the responsibility of the facilitator(s). A team can work privately (without accepting new members) only if this decision can be clearly justified.

Table 1. Proposed structure for a typical 30-day sprint including the phases preparation (orange), implementation (green), evaluation (dark blue) and solution/decision (light blue)

Week	Day	Phase
1	1-7	Organization of teams by facilitators (4a)
	1-3	Ask contributors for preferences
	4-7	Draft plan and allocate tasks
2 & 3	8-21	Implement work (4b) or present (4c) and discuss (4d) outputs from previous sprint
	21	Report to citizen science board and steering members using a standardized template Possibly apply for cohort results (4e)
4	22-25	Revise outcomes across teams (teams may even be required to revise each other if not sufficient global facilitators) • if application for cohort results: By citizen science board(s) If no application for cohort results: By citizen science board(s) or volunteering steering members
(4)	26-27	Collation of outcomes and decision making
	28	**End of sprint**: Present outcomes and voting options via website / social media / platform
	29-30	Based on outcomes of day 28: team decides whether to continue (and inclusion of new members) and can start planning the next sprint

4.3 Community motivation

Playfulness can promote reflection processes and learning as part of RRI. Furthermore, gamification can also improve the accuracy of tasks (Wazny, 2018). van der Meij et al. (2017) identified playful design elements via a narrative review. Four activities (Table 2) and the following three process requirements were identified:

- Experimentation space: Voluntariness, relaxedness, judgement free
- Focus: Steps, clearness of tasks and content (sub-topics)

- Stimulating guidance: People or objects that stimulate motivation

Possible measures could be considered

- quantitative measures, e.g. count of contributions, measured/estimated/reported time (total; for innovation, learning, engagement, dissemination, …)
- qualitative measures: user feedback (likes, follow, recommend; possibly rating); other measures of trustworthiness (Wazny, 2018)

Based on that, we could offer

- badges,
- automated suggestions to users when logging-in to the platform based on
  - contents already stored in the database and
  - users' interest and experience (interactive feature) to saves users' time in identify relevant topics / tasks. Details of such gamification features will be elaborated further.

Details need to be discussed further.

Table 2. Activity principles identified by (van der Meij et al., 2017) via a narrative review.

Activity principles	Description
Narration	- contents in story structure, e.g. personal stories, fictitious and funny aspects) - effect: engagement by empathy; the narratives encourage users to look at aspects from someone else's perspective
Imagination	- (Intuitive) thinking about the unknown - linking a multitude of unusual and new ideas (by association)
Action-reflection	- carry out (a multitude of) actions (via teams / tasks) - immediate reflection on actions (monthly reflection during sprints; see section 4.2) - 'do-it-yourself-science', where citizens can playfully explore and experiment, with co-citizens, scientists or other societal actors
Co-creation	- Collaborative creation of thoughts, settings/environments or objects, converge to an end-result

4.4 Process coordination

The steps proposed for JoinUs4Health resemble the process by Ulbrich and Wedel (2021) (impetus = suggest, decision = vote an select, concept = plan, execution = implement, assessment = review, exploitation = disseminate and feedback). Ulbrich and Wedel (2021) made the experience that individual process components can be merged or performed in parallel, but the process components themselves remain the same. Criteria for an item to go through the steps of the concept are outlined in Annex II.

1 Impetus	2 Decision	3 Concept	4 Execution	5 Assessment	6 Exploitation	7 Feedback

Figure 6. Phases and process flow of the crowdsourcing model proposed by Ulbrich and Wedel (2021) (own representation)

Once a team has been formed or task-based work has started, the assigned facilitator coordinates subsequent process activities. Table 3 summarizes first thoughts on responsibilities and rights of facilitators.

Table 3. First thoughts on responsibilities and rights of facilitators

Group / description	(Working) teams	Task-based work
Responsibilities		
coordinating the team members and assigning tasks (if applicable)	X	X
documenting a plan for the respective sprint (ideally with input from team members) and communicating the plan by day 7 of the sprint	X	X
coordinate team activities, i.e. virtual meetings and other forms of exchanges	X	-
ensures that members adhere to communication rules and other rules and guidelines	X	X
is the first-level conflict solver; if no resolution is found, the case is passed on to the supervisor, who decides on next steps	X	X
Rights		
open and close a team and inviting members to the team	X	-
warn members in case of non-adherent behaviour	X	X
ban members from a virtual meeting or even a team	X	-

4.5 Process monitoring and evaluation

Key indicators

Annex IV shows two examples of set of composite indicators developed for

- **RRI** (Figure 7a): anticipation, reflexivity, inclusion deliberation, responsiveness and knowledge management (Lubberink et al., 2018) and
- **OH** (Figure 7b): operational (OH planning, thinking and working) and infrastructure (learning, sharing, systemic organisation) indicators (Rüegg et al., 2018).

Both frameworks offer key activities, strategies and examples. The suitability of these two frameworks and potential other frameworks need to be further explored. Key performance indicators will be defined in Deliverable 7.1 "Monitoring and evaluation (M&E) framework" (due in August 2021) incorporating existing frameworks.

Evaluation of the designs against requirements

Community members will be able to propose additional features to be added throughout the project. These suggestions are submitted to the platform and elaborated if they receive sufficient community support and are considered valuable for the overall aim. Promising features shall be implemented throughout the project period as long as the workload does not exceed budget allocations.

The effectiveness of features needs to be evaluated and new features pilot tested with a set of volunteers. Usability-test reports and user survey reports need to be integrated as part of the platform.

4.6 Self-regulation of the system

After some time, increase self-regulatory capacity of the system. For instance, if a threshold is reached (e.g. percentage of unassigned tasks), certain features of the platform may be turned off to compromise for the lack of contributors. However, an effective fine-tuning system needs to be established. The introduction of such thresholds is a gamification feature, which emphasizes the need for community-drive. If insufficient volunteers are available, fewer options can be offered / supported.

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Annex I Project objectives and work packages

JoinUs4Health includes the following specific objectives:

1. **ESTABLISH** and **REVIEW** a conceptual framework

JoinUs4Health will establish an RRI advisory panel with seven representatives from international RRI initiatives and projects experienced with the implementation of institutional changes and systematically consult this panel throughout the project. A citizen science board will be created for each cohort including different groups of local stakeholders. The multi-disciplinary consortium will conduct systematic needs assessment and consultation of various stakeholder groups to assess barriers, opportunities and preferences via online questionnaires and virtual, participatory workshops. These activities form the basis for the revision of the conceptual framework.

2. **DEVELOP, TEST** and **APPLY** technology to facilitate engaging various actors as part of cohort research

JoinUs4Health will develop a project website and a secure technical platform. The platform will provide a user-friendly interface

and a secure environment for researchers, citizens and other groups to interact by collating, categorizing and promoting research questions (low-level interactions). Working groups will be formed allowing high-level interactions to address prioritized research questions. In years 2 and 3 the platform will attract per country annually at least 200 new users (total: 1200) and promote the work of at least 20 working groups (total: 120).

3. **EXPLORE, IMPLEMENT** and **MONITOR** institutional changes and incorporate RRI into the governance framework of three institutions conducting cohort studies

JoinUs4Health will gradually apply six institutional changes at the cohort institutions with input and support from P2 and the RRI advisory panel. Implementation will be tailored to the specific university and country settings. Therefore, details will be revised involving university representatives, the citizen science board and other stakeholders. The institutional changes will be gradually implemented. All institutional changes will be designed so that they can be sustained after the end of the project. Moreover, by increased communication and organized efforts the partners will strive to encourage other institutions, like local authorities, medical and health organisations, schools etc., to implement institutional changes as well to contribute to RRI.

4. **ADVANCE** RRI and citizen science into the mainstream of public engagement, science communication and education

JoinUs4Health will leverage experience, infrastructure and expertise from existing educational training programmes from the Erasmus MC – University Medical Center Rotterdam to stimulate involvement of pupils, students and citizens in science. The infrastructure and design of these programmes will be adapted and subsequently exchanged among other consortium partners to efficiently integrate education about RRI and science in general at an institutional level. This will also benefit mutual learning among consortium partners. With input from citizens, a core curriculum for RRI will be conceptualized for researchers and healthcare professionals. Dedicated RRI online courses and webinars will be designed for different levels of educational attainment and made accessible for both citizens and researchers. To practically engage citizens, pupils and students in science, research visits through summer schools, practical courses and secondments will be organized.

5. **PROMOTE** engagement and **COMMUNICATE** and **DISSEMINATE** outputs via traditional and innovative means

JoinUs4Health will promote interactions and engagement during planning (consultation, uptake of research ideas), implementation (enrolment of new participants), analysis and interpretation (working groups) as well as dissemination of results (pilot testing of materials, knowledge promotors). This includes systematic engagements via the platform and targeted activities (e.g. science & health festival, research café). Furthermore, JoinUs4Health will develop and apply communication and

dissemination strategies to target different stakeholder groups via traditional (newsletters, webpage, newspaper, radio) and non-traditional means (social media, knowledge promoters, webinars, virtual conferences). Long-term sustainability may be promoted via demonstrating the benefit of the citizen-driven research for policy and business strategies.

Annex II Background

Annex II.1 Cohort research

Short overview of the cohort institutions
- cohorts produce continuously growing databases of high-quality data, which form a valuable resource for addressing health-related questions applying principles of RRI   - Features: - option to compare health between three countries   - data on over 27,000 participants   - time period of up to 31 years   - vast range of existing scientific publications and other outputs   - high throughput of new outputs (e.g. manuscript submissions, research proposals)   - medical and scientific expertise   - Institutional changes will be implemented to encourage RRI practices at their institutions

Three of the JoinUs4Health partners have been implementing population-based cohort research for up to 31 years, which resulted in data sets including over 27,000 participants (Table 4):

- Study of Health in Pomerania (SHIP) in Germany since 1997 [6], n = 8,728;
- Rotterdam Study (RS) in the Netherlands since 1989 [7], n = 17,932;
- Bialystok Polish Longitudinal University Study (PLUS) in Poland since 2018, n = 888.

Until 12/2023 approximately 5,000 additional participants will be enrolled as part of SHIP (n ≈ 3,000), PLUS (n ≈ 2,000) and RS (n ≈ 100).

The three cohort projects were designed to assess the prevalence and incidence of common risk factors, subclinical disorders and clinical diseases and investigate the complex associations and interactions among them. Therefore, they apply a wide range of examinations rather than focussing on a given disease. Protocols include for example medical examinations, laboratory diagnostics, questionnaires on socio-demographic and risk factors as well as highly specialised examinations such as whole-body resonance imaging.

Table 4. Overview of the decline in response in different cohorts worldwide at baseline examinations

Cohort study	Country[a]	Name of cohort	Start	Number of participants[b]	Response rate
SHIP	DE	START	1997	4,308	68.8%
		TREND	2003	4,420	50.1%
		NEXT	2021	[0/4,400]	not assessed
Bialystok PLUS	PL	PLUS	2018	[888/4,000]	45.4%
Rotterdam Study	NL	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	45.3%
Total				27,910	

[a] countries: DE: Germany, PL: Poland, NL: the Netherlands
[b] in square brackets: number of participants enrolled as of 04/2021 out of targeted number of total participants for this cohort

The proposed concept poses the following requirements to the cohort institutions:

- stronger engagement of and communication and dissemination of cohort results to its participants, target populations and society as a whole,
- staff is enabled (in terms of 'competence', 'rewards' and 'space') to live up to societal commitment and take on different roles,
- environment creates and supports an open dialogue with their customers (participants), target population and society as a whole, and
- internal incentive system acknowledges the efforts made in the field of RRI and ethics.

Annex II.2 Crowdsourcing and Responsible Research and Innovation

Annex II.2.1 Responsible Research and Innovation

Responsible Research and Innovation (RRI) can be regarded "as a new logic of re- search and innovation, transforming research practices across disciplines into being more deliberative, inclusive, and anticipatory." (Forsberg, 2021). JoinUs4Health has the potential to integrate RRI perspectives in all research and innovation practices of the project and stipulate change in practices of the involved cohort institutions via the work packages "Institutional changes" and "Formal, informal and non-formal education" (see Annex)..

RRI

- implies that different groups of societal actors work together during the whole research and innovation process to better align both the process and its outcomes with the values, needs, concerns and expectations of society (!!! INVALID CITATION !!! (Owen, Macnaghten et al. 2012, Von Schomberg 2013, Zwart, Landeweerd et al. 2014));
- although communication is a crucial part of the RRI approach, communication is not seen as solely dissemination or scientific knowledge-transfer, but as an intrinsic component of the methodology of innovative research, fostering multi-actor and public engagement and enabling easier access to scientific results;
- in contrast to the traditional deficit model (in which a knowledge deficit is assumed for non-experts, leading to 'explaining' as the communicative model), the focus is on knowledge deficits of producers and experts, i.e. the difficulty of predicting whether and how techno-scientific innovations will work or be adopted in practice;
- the knowledge-creation process takes into account different types of knowledge (e.g. scientific and experiental knowledge);
- The goal is not to predict, but to explore possible scenarios and to co-create the future via mutual learning exercises.

However, it is also important to acknowledge

a) the complexity of societal challenges, for which people's creativity to develop solutions shall be mobilized,

b) the complexity of the task of managing a community across three countries comprised of different groups of actors and personality types, and

c) potential critical aspects of RRI in general, which have been discussed by (Leitner and Weber, 2019) and are summarized in Annex II.2.4.

Annex II.2.2 Crowdsourcing

Similarly to RRI, crowdsourcing is not a rigid methodology. Different definitions as well as application types and environments have emerged. The broad crowdsourcing definition

proposed by Estellés-Arolas and L. Guevara (2012) was proposed to cover all various scenarios:

- *a type of participative online activity in which a [crowdsourcer*] proposes to a group of individuals of varying knowledge, heterogeneity, and number, via a flexible open call, the voluntary undertaking of a task;*
- *the undertaking of the task, of variable complexity and modularity, and in which the crowd should participate bringing their work, money, knowledge and/or experience, always entails mutual benefit;*
- *the user will receive the satisfaction of a given type of need, be it economic, social recognition, self-esteem, or the development of individual skills, while the crowdsourcer will obtain and utilize to their advantage that what the user has brought to the venture, whose form will depend on the type of activity undertaken.*

* crowdsourcer: an individual, an institution, a non-profit organization, or company

Different groups of crowdsourcing types have been proposed, e.g.

- human computation, crowd competitions and peer collaboration (Hansson et al., 2019);
- microtasking, information pooling, broadcast search, and open collaboration (Blohm et al., 2017); and
- crowdstorming, crowdvoting, crowdsolving and crowdcreation (Wedel, 2021).

The JoinUs4Health concept combines different crowdsourcing types in one concept, regardless of the grouping approach applied.

Annex II.2.3 Convergence of RRI and crowdsourcing

A recent paper described the combination of RRI and crowdsourcing as part of an RRI project funded by the Research Council of Norway (Molla et al., 2018). However, to the authors' knowledge, no other publication has specifically drawn the link between crowdsourcing and RRI. Other instances where crowdsourcing has been mentioned in relation to RRI was in the context of gathering research questions in the two projects conducted by the Ludwig-Boltzmann-Association in Austria[7] and crowdsourcing being suggested as a methodology for co-creation on the RRI Tools website[8].

Publications on crowdsourcing have increased rapidly in recent years, but the current state of crowdsourcing theory is a mixture of empirical work, shared methods and concepts and distant theoretical ideas (Wedel, 2021). The review of existing methods and proposed systematization approach by Wedel and Ulbrich (2021) was used as a baseline for our design specifications.

Annex II.2.4 Potential critical aspects, drivers and barriers for RRI

Potential critical aspects also need to be considered when specifying requirements for the JoinUs4Health platform. Leitner and Weber (2019) discussed critical aspects of changing research and innovation patterns and related challenges, taking into account results from

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[7] https://www.youtube.com/watch?v=-IR1r6rjGiY&feature=youtu.be
[8] https://rri-tools.eu/how-to-stk-bi-how-to-boost-creativity-and-involve-people

three foresight projects[9,10,11]. Whilst new forms of open and user driven innovation can speed up innovation, other stakeholders experienced that the innovation process may also slow down as innovation may be laborious, typically loosely coordinated and slow. This variety of experiences has also been documented for crowdsourcing applications (Blohm et al., 2017).

Table 5. Critical aspects of changing research and innovation patterns based on the findings from three European foresight projects

Critical aspect	Potential consequence	Preventive JoinUs4Health action(s)
Collective experimentation is typically loosely-coordinated and slow	Slowdown of the innovation process	Apply processes, structures and voting mechanisms to provide strategic oversight and a continuous feedback mechanism to the platform users; team work is divided into four-weekly sprints
High levels of participation may only produce only average quality	Trade-off between participation and breakthrough research and innovation	JoinUs4Health is not just about innovation and breakthrough research, but also about delivery and reach (see section 0) and acceptance of societal changes; therefore, excellence criteria (e.g. speed, quality) may differ; in many cases systematic exchange as such is considered an important step to break down barriers and enhance understanding of diverse perspectives
Time consuming to support small and specific groups	Institution-driven long-term engagement of small groups is unsustainable	Transfer scientists' skills to enable the community to autonomously improve and disseminate their own initiatives (i.e. toolkits, training, train-the-trainer)
Potential fraudulent behaviour in academia or business; data protection and privacy concerns	Reluctance of groups of actors and individuals to engage in open innovation	Provide clear documentation of GDPR and IPR guidelines and procedures in case of any breaches including conscious provision or distribution of false or misleading information; community encouraged to advance initial baseline agreements if considered necessary; provide clear guidelines, procedures, behavioural rules, roles and responsibilities
More and more individuals will be part of the innovation imperative without gaining the returns for their efforts	A 'creative poor' class may emerge which cannot benefit adequately from the innovation dynamics	Keep society as end-user in mind at all times to justify individual efforts
Lack of preparedness of individuals to accept negative short-term effects	Hinder long-term transitions towards a more sustainable ecosystem	Aim for long-term engagement of three local societies to raise societal health awareness and encourage community-level support and ideas
Pseudo involvement	Only superficial adjustments whereas the true power mechanisms are	Design transparent concept and continuously thrive to demonstrate societal benefits; implement

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[9] The Research and Innovation Futures (RIF) project analysed new and emerging ways of doing and organising research in universities, research organisations, companies and civil society (grant no. 289058).

[10] The Innovation Futures (INFU) project explored patterns and structures of innovation, their potential for different sectors and implications for economy and society (see http://innovation-futures.org; grant no. 225229).

[11] The Forward Visions on the European Research Area (VERA) project explored scenarios of the European research and innovation landscape by 2030 (see http://eravisions.archiv.zsi.at/index.html; grant no. 2907059)

Critical aspect	Potential consequence	Preventive JoinUs4Health action(s)
	hidden behind a "participatory facade"	institutional changes with society as main beneficiary in mind.
Criminal actors may threaten privacy and manipulate virtual systems by generating false preferences	Negative effects in society and reduced output and monitoring quality	Privacy issues (Xia and McKernan, 2020), user rights, transparency of processes and outcomes as well as ethical aspects and intellectual property rights. Content policy, interoperability and standardisation issues also play a role
Pervasive use of standardised innovation processes	Hamper creativity and the innovation potential by restricting the room for radical innovation	Find a balance between requirements and flexibility

Table 6. Structural, cultural and interchange related drivers and barriers to implementing RRI in organisations, using a framework derived from neo-institutional theory

Type	Drivers	Barriers
Structural	Dedicated (pilot) programmes, infrastructure, and organisational units dealing with the key or dimension or integrating several of them into a coherent bundle	Lack of resources (money, time, people, training, expertise)
Structural	Organisational mandates, regulations, policies, strategies and organisational goals	Lack of incentives
Structural	Guidelines, procedures and organisational routines (including planning processes) in place to support the key or dimension or bundles of them	Lack of strategies, policies, frameworks, systems, and formal structures supporting practices pertaining to the aspect of RRI
Cultural	An organisational culture, expressed in established organisational values and organisational identity, that fits the key or dimension and that supports it	Lack of knowledge and awareness
Cultural	An overlap with traditional scientific values and norms, that include the training of next generation academics	RRI seen as an add-on, rather than as a central activity of the organization
Cultural	Institutional entrepreneurs, managers and other 'translators' that further a particular RRI key or dimension, or several of them, in the organisation	Classic academic values of autonomy and merit that operates in tension with RRI
Cultural		Ingrained ideas of innovation that operates in tension with RRI
Cultural		Perceived lack of clarity in the RRI concept
Interchange	National policies, regulatory frameworks, laws and monitoring systems, as well as international benchmarks driving policies, such as the PISA assessment	Lack of policies and clear mandates
Interchange	Politically initiated programmes	Lack of clarity in various ways
Interchange	Demands from funding agencies, and the EC, particularly through its framework programs and their assessment criteria	Lack of perceived interest and pressure from the public and political field (including translation issues)
Interchange	Expectations from stakeholders and the public, as well as expectations of expectations, creating pressure	Organisations not held accountable
Interchange		Privacy and commercial interests
Interchange		Other concepts dominate the public discourse (e.g. accountability or sustainability)

Annex II.3 Target groups

Key take aways:
- our focus is society, however cohort participants receive a special focus due to their commitment to cohort research   - five stakeholder groups are specifically distinguished, that is   - citizens / citizen associations   - scientists   - education community (pupils over the age of 16, university students)   - policy-makers   - business / industry   - Two representatives from each of these groups shall be invited to join a Citizen Science Board in each country; if boards are not yet completely recruited other stakeholders from the group shall be invited to provide feedback

Target regions: Study region of the three cohort studies SHIP (Germany), Rotterdam Study (the Netherlands) and Bialystok PLUS (Poland)

JoinUs4Health includes different sub-communities:

- According to RRI framework, we distinguish between five RRI groups: Citizens, researchers, education community, business/industry, citizens

Participation requires internet access since JoinUs4Health relies on virtual tools and exchanges. Key outputs of the project can be disseminated via other means (newspaper, radio) to enhance reach. Furthermore, digitally connected peers (family members, friends) may spread the word of JoinUs4Health (see indirect beneficiaries in section).

Annex II.4 Topic

Key take aways:
- central topic: Health   - scientific input primarily by cohort institutions, but also by scientists from other institutions within and outside the primary study regions

The overarching topic is "Health" as the cohort partners provide opportunities to use population-based research in closer proximity to societal expectations and needs and benefit from the innovation potential and ideas of a large, diverse community. Networks of the cohort and other partners are used to supplement this diversity of knowledge and resources.

Health is opened as a topic in general regardless of whether the specific aspect under question has been covered by any of the cohort partners. Furthermore, scientific input is not limited to the cohort partners alone to allow interpreting scientific evidence in light of other research. Hence, any researcher and citizen of the partnering countries shall eventually be able to access the platform, resources and network generated via the JoinUs4Health project.

Table 7 lists topic as criterion for accepting a suggestion and promoting it via JoinUs4Health.

Annex II.5 Restrictions

<table>
<tr><td>Key take aways:</td></tr>
<tr><td>

- need for controlled environment for exchange
- restrictions apply (tone of debate, scientific basis, population-based focus)
- control mechanism need to be applied to promote joint-decision-making, whilst protecting the mechanism from abuse (see section 3.3.2)

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We introduce a few starting limitations. Based on experience, community members can propose additional restrictions and elaborate on rules and guidelines throughout the projects.

1. Create socially safe spaces for exchange
    a. *Tone of exchange*: we aim to provide a socially safe environment for exchange, i.e. rules are in place to limit for example derogatory, aggressive or other non-accepted forms of behavior and conscious distribution of false information
    b. *Scientific basis*: Purely political debates not backed by scientific evidence or based on scientific approaches are not promoted (described as criterion in Table 7)
    c. *Control mechanisms* are put in place to ensure the provide a socially safe space for exchange, including
        i. no open dialogue
        ii. only facilitated teams, where facilitator has signed agreement to ensure the guidelines
        iii. upload of submissions and contributions only following review of a member
        iv. citizen science board, monitoring and evaluation group and scientific steering committees of the cohort institutions keep ultimate control in case of a disagreement.
2. Population-based focus (described as criterion in Table 7)
    a. JoinUs4Health does not aim to provide personal feedback on health issues
    b. a population-perspective is encouraged throughout to generate viable benefits to society as a whole
    c. different types of knowledge (e.g. experiential knowledge, place-based knowledge) and perspectives are integrated into the knowledge-making process as valuable inputs in addressing societal challenges.
    d.

Annex II.6 Access points

<table>
<tr><td>Key take aways:</td></tr>
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- Offering a variety of access options is considered a key necessity to attract individuals with different backgrounds and interests and thus widen the reach
- The JoinUs4Health platform shall allow targeted linkages with the JoinUs4Health work packages institutional changes, education and dissemination/engagement
- Besides the traditional crowdsourcing process flow (here termed: suggest, vote, select, prepare, implement, discuss, review, disseminate), the JoinUs4Health process can involve only some of the steps, apply these in different sequence and access them via different routes

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These steps can be applied in a flexible manner, thus opening different access routes to the JoinUs4Health framework. The following examples illustrate the variety of access options.

- Scientist presents manuscript prior to submission or published paper

- Scientist presents preliminary data set and engages (facilitator and) community (can then respond directly with customized results)
- Citizen takes education path and engages in teams as part of training
- Citizen is unsure and looks for a buddy to help with first steps; any community member ocan act as a buddy...
- Citizen is interested in German title and abstract of a cohort paper and asks for easy translation (e.g. into citizen- or local language)
- User would like contribution on platform translated
- Project-tasks: Project team looks for support with networking
- Within cohort institutions:
  - When suggestion on platform has received considerable support, task is posted internally within cohort institution looking for scientist, student, medical staff etc. who may want to engage, contribute etc.
  - A result application of a team is approved but a scientist is needed to conduct the analysis: Institute leaders nominate staff members (and are rewarded in some way)
- Business or Federal Ministry of Health sets a Challenge, e.g. a complex problem requiring creative solutions
- Scientists want to engage citizens in writing a paper
- Policy maker posts challenge via the platform
- Medical student looking for a research project
- Scientist from any institution looking for aspects related to own project

Annex II.7 General considerations

Sourcing individuals from the three cohort studies provides access to a large number of heterogeneous individuals in terms of knowledge, personalities and preferences. Thus, the JoinUs4Health community and sub-communities (e.g. certain age groups) present opportunities but also challenges.

Here is an overview of general considerations when choosing platform features and tools:

Diversity: A circular process shall be established where scientists, citizens and representatives of other RRI groups have the option to engage with each other as part of a flexible framework, which values and nurtures diversity and thus promotes peer-learning, mutual learning and systematic exchange. Processes shall be encouraged to facilitate true two-way exchanges, joint decision-making and mutual learning. Special emphasis is placed on reaching out to different groups of actors, e.g. via different types of events (see (D6.1) on project website) and dissemination and engagement approaches (see M6.1 on website).

Collective intelligence: Listening to questions, experiences and concerns of citizens and engaging in targeted exchanges provides opportunities to enhance direct benefit of society from (cohort) research and make cohort research more responsive to ideas, expectations and needs raised by citizens and representatives of other societal groups.

Transparency: The mechanism needs to be transparent to promote trust and understanding and comply with FAIR principles, i.e. Findable, Accessible, Interoperable and Reusable. Also the platform developed as part of the JoinUs4Health project must be free and open source so that other (research) institutions can apply it in the future and can understand how the platform and the underlying algorithms wo.

Inclusiveness: A variety of interactions and choices shall be offered so that individuals with different personality types, interests and time availabilities as well as levels of knowledge, knowledge types and expertise can find activities or outputs matching their interest. The aim is to generate a

highly satisfactory user experience when engaging with JoinUs4ealth regardless of whether users want to inform themselves (passive users), actively engage (active users), learn or promote.

Accessibility: Visual and physical disabilities and offering contents in national languages for non-English speakers. For blind people who use assistive technologies messages of an image can only be conveyed if the message is also captured in the caption of the image.

Inclusiveness is key to reach a large part of the population with individuals from diverse groups. Therefore, it is important to recognize that there are differences in personality types, capacities, interests and needs:

- active user, who actively contributes (focus: task-based work, innovation)
- passive user, who benefits from results (focus: delivery), andindirect beneficiary, who doesn't directly engage with or benefit from JoinUs4Health, but hears about the project and its activities through peers and thus builds up a positive perception (focus: reach of peers across wide range of population strata).

Learning is regarded as a transversal process rather than a distinct process from the knowledge-making interactions. The learner profile is embedded in the passive and active user profiles, since the way that people will mutually learn in the platform is through experiential learning.

This distinction of user / beneficiary types leads to the distinction between task-based work, innovation, delivery and reach.

Task-based work: For the mechanism to run sustainably, community members need to increasingly take over system-relevant tasks. Further tasks may arise from active teams or user requests (e.g. translation).

Innovation: Engagement of diverse group of actors to jointly address societal challenges of our time.

Delivery: The aim is not just to disseminate, but to deliver what is a) wanted / needed and b) currently happening to generate a direct feedback loop between society and science.

Reach: Rather than targeting the top-creative minds, the aim is to provide suitable formats of dissemination and engagement to as wide a part of the population as possible.

Annex II.7.1 JoinUs4Heath community and sub-communities

Upon registration, key information needs to be collected to be able to group individuals into sub-communities. This allows an investigator (e.g. team facilitator, citizen etc.) to target certain sub-communities (e.g. only cohort participants or only policy makers).

Furthermore, users can be offered additional choices, e.g. whether to sign up to additional offers (e.g. newsletter, buddy system) or tools provided by external partners, thus opting in and out of additional sub-communities.

Annex II.7.2 Semi-controlled environment

The JoinUs4Health platform shall provide a safe environment for exchange, where decision-making, quality of information and tone of exchange is controlled via the following measures:

- no forum and thus no open dialogue unless a certified facilitator takes responsibility for guiding the exchange,
- free text submissions and generated outputs undergo prior review by two independent volunteering community members,
- rules and guidelines will be provided or developed to establish safe environment for exchange,

- citizen science boards (and monitoring and evaluation groups) act as primary monitoring and decision-making body, and
- if cohort resources are applied for, the scientific steering committee of the respective cohorts makes the final decision.

Annex II.7.3 Semi-open access

Access to cohort results / data

Cohort data that are already available and to be provided for JoinUs4Health research etc. will be still owned by the participating institutions (Background IPR).

- no access to individual level data unless a cohort representative or other individual with a link to a cohort representative has sufficient analytical expertise and signs a contractual agreement following the rules for data application of the cohort institution
- requirement to submit application for aggregated cohort results or in case of an agreement to be signed individual-level cohort results
- applications of teams for cohort results are revised by the scientific steering committee(s) of the cohort institution(s) after prior approval by the citizen science board(s)

Access to data dictionary, metadata and descriptive results

- For SHIP, a data dictionary in German in English is available for all its first two sub-cohorts SHIP-START and SHIP-TREND

Outlook:

- Statistical pipelines could be increasingly adapted to provide direct access to descriptive results (univariable) and associations between two variables (bivariable).
- Both SHIP and the Rotterdam Study are part of the EUcanshare consortium[12], which provides open access to data dictionaries and metadata (in progress).

Access to (open source) publications and abstracts

Efforts will be made to link publications with topics within the platform, with links to abstracts (ideally translated to the national level), open source manuscripts or summaries of published contents in easy-to-understand language using different communication methods and tools

Access to outputs produced via JoinUs4Health

The partners agree that the direct results of the project (platform, information strategy, reports, policies) will be available for the general public as open source. The results of the research that is fostered by the proposal will be owned by the directly involved scientists and institutions, based on the local policies and agreements (Foreground IPR).

Access to platform, algorithms and tools

Open source: The core platform shall be a modular open source software, so future changes and adjustment for particular needs will be feasible for anyone who decides to adapt it to local conditions. Identification of specific requirements and functionalities for the platform during the collaboration with the citizens may lead to adaptations of the platform throughout the project. A general requirement is that the software is free of charge and comes with a free license, like GPLv3. Links to closed-source tools can be offered in some circumstances but need to remain optional.

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[12] http://www.eucanshare.eu/

Annex III Criteria for an item to go through the steps of the concept

This section proposes criteria for an item, i.e. a submitted topic, question or suggestion, to transfer from submission to the platform (step 1) to the application of access to cohort data (step 4e) and access to networks. Numbers in brackets refer to the numbering of steps in Figure 3. The introduction of threshold represents a basic gamification feature (Wazny, 2018).

Annex III.1 Criteria for a suggestion to be selected for high-level interactions

Suggestion à database entry is made visible to platform users (step 1)

A suggestion is made visible to platform users if the criteria in Table 7 are met. More detail on the criteria 'health-related' as well as 'scientific basis' and 'population-based focus' can be found in sections 0 and 0, respectively.

Table 7. Criteria for a suggested item to be made visible to platform users

Criterion	Details
Health-related	Health as general topic regardless of whether the specific aspect under question has been covered by any of the cohort partners
	Besides classical medical evidence, evidence, experience and opinions on alternative medical approaches is welcomes as long as it allows a science-based exchange.
Scientific basis	if there is a disagreement between the two reviewers as whether a suggestion should be made public, differences in opinion are documented and a 2nd round of review requested
Standardized	- suggestion follows a standard template to allow efficient access via the JoinUs4Health database - individual, who is making the submission, is encouraged to follow the template, but can also make a free text submission, in which case a voluntary community member needs to transfer the details to the standard template
Reviewed	- submission is revised by two independent reviewers, i.e. community members (initially backed by project staff) - reviewers receive basic training what to pay attention to when reviewing submission (e.g. no personal information, assurance of acceptance criteria - reviewer documents assessment in the database; the assessment is only visible to moderators, supervisors and facilitators - moderator, supervisor or facilitator[a] decides whether to make the (revised) submission public

Annex III.2 Criteria for basic teams

Suggestion à formation of team

Once criteria listed in Table 8 are met: The suggestion enters the high-level interaction phase, i.e. formation of teams.

A team is active for at least one sprint, but can continue thereafter or pause for some time, after which another team (two different facilitators) or the same team can continue the work or apply different approaches using the outputs of the previous sprints.

Table 8. Criteria for a submission to lead to the formation of one or more teams

Criterion	Details
Votes above threshold	- sufficient „interest" from community - threshold may depend on the level of activity of volunteers
Minimum number of contributors identified	the willingness of contributors to a given task or topic is assessed via the active vote

Criterion	Details
Two facilitators have been identified	- anyone can apply to become a facilitator, after which a short training and assessment are performed - facilitators are monitored to ensure that minimum quality standards are met and standard operating procedures followed

Formation of team à implementation of planned sprint activities

Once criteria listed in Table 9 are met, high-level (team) interactions may start

Table 9. Requirements for the formation of a team

Criterion	Details
Sprint topic	based on willingness and expertise of contributors, suggestion is broken down to manageable pieces, which can be addressed in a single sprint (sprint topic)
Methodology defined	e.g. individual contributions (shared review), focus group discussions, Delphi survey, …
Expected output specified	to document progress for future teams

Implementation of planned sprint activities à reporting of outputs

At the end of each interaction

- document outputs
- short internal review (e.g. satisfaction of contributors, …)

Table 10. Criteria for the implementation of the team

Criterion	Details
Standard procedures are followed	based on protocol, provide some flexibility
Provide safe environment to interact	
1 or more facilitator(s) take(s) lead	facilitator responsible for following guidelines (ethics, communication rules, …)

Reporting of outputs à review and dissemination of outputs

- generate tangible outputs
- open them for discussion
- capturing feedback by team members and the facilitator(s); only aggregated feedback is made visible after the user has participated in at least five sprints

Table 11. Criteria for dissemination of team results via the platform, website and social media

Criterion	Details
Output is documented	to inform future teams and the community
Feedback is gathered	light external review from users outside the team
Dissemination offered	each team shall offer virtual exchange open to community if sufficient interest (led by facilitator)

Continuation of teams

Table 12. Criteria for the continuation of teams

Criterion	Details
No concerns are raised	If a concern is raised by any JoinUs4Health user (team member or not), a review by two reviewers is requested

Criterion	Details
	• if no solution can be found, the case is presented to the JoinUs4Health citizen science board, the wider JoinUs4Health community or a specially established jury • a team can be paused temporarily until a decision is reached and may be permanently suspended if the citizen science board, JoinUs4Health community or invited jury consider the concerns justified
At least one of the two facilitators is willing to continue	if two new facilitators take over, technically a new team is formed even if the members persist
Requirements of the previous sprint have been fulfilled	planning and reporting requirements

Annex III.3 Criteria for advanced teams

If the criteria listed in Table 13 are met, teams can receive access to

- aggregated cohort results or
- individual-level cohort data (if analytical expertise and contractual agreement) or
- scientific expertise or
- cohort / JoinUs4Health networks.

Table 13. Criteria for applications and being granted access to cohort resources

Criterion	Details
Team or at least facilitator has good track record	to inform future teams and the community
At least one round of high-level interactions has taken place	the planning, implementation and reporting of a sprint need to adhere to minimum requirements
Proposal is submitted	including a protocol describing the background, objective, planned activities / analysis / use of resources etc.
Proposal is accepted following review	the submitted proposal is reviewed in two-steps, i.e. by the citizen science board (1), and the scientific committee of the cohort institution(s) (2)

Annex IV Evaluation examples

a)
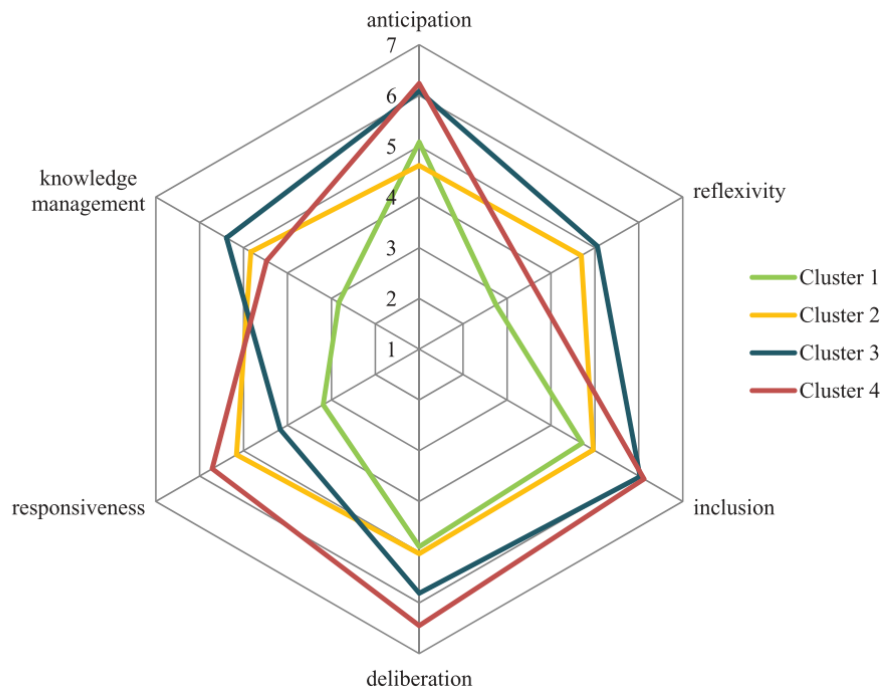
b)
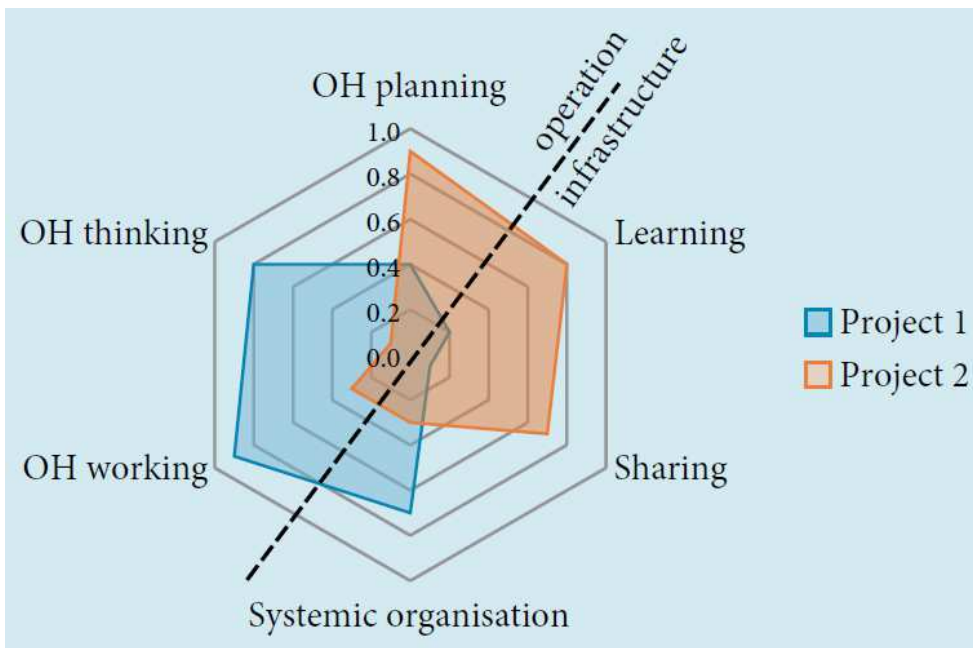
Figure 7a and b: Examples of composite indices developed for the evaluation of RRI (Lubberink et al., 2018) and One Health (Rüegg et al., 2018) activities

Spider diagrams (also called radar charts) provide an easy to understand summary of composite indicator indices for a given or different groups of entities (e.g. projects, clusters, in case of JoinUs4Health: teams). Figure 8a (RRI): 42 self-assessment questionnaires of industry representatives (response rate: 15.5%) grouped into four clusters via cluster analysis; Figure 9b (OH): two fictive projects.

Glossary

actor   a subgroup of stakeholders (see there for distinction) such as 'any individual, group or organisation who acts, or takes part' in the context of the OH initiative [see Rüegg et al. (2018)]

challenge   well-formed problem statement, with a clearly defined process and whose solution has value to a company, an institution or society

collective intelligence   a group or a team's combined capacity and capability to perform a wide variety of tasks and solve diverse problems. Collective Intelligence has been found to consistently predictive of the future performance of groups and teams (Chikersal et al., 2017)

Note: The primary difference between IQ (individual intelligence) and CQ or collective intelligence is the social dimension and the ability of groups to achieve unity of purpose, action and thought. Teams with high levels of CQ achieve a state of interdependance and flow when they are working together.

crowdsourcing
- a type of participative online activity in which a [crowdsourcer*] proposes to a group of individuals of varying knowledge, heterogeneity, and number, via a flexible open call, the voluntary undertaking of a task
- the undertaking of the task, of variable complexity and modularity, and in which the crowd should participate bringing their work, money, knowledge and/or experience, always entails mutual benefit
- the user will receive the satisfaction of a given type of need, be it economic, social recognition, self-esteem, or the development of individual skills, while the crowdsourcer will obtain and utilize to their advantage that what the user has brought to the venture, whose form will depend on the type of activity undertaken

Source: (Estellés-Arolas and L. Guevara, 2012)

effectiveness   accuracy and completeness with which users achieve specified goals [see ISO (2019)]

efficiency   resources used in relation to the results achieved [see ISO (2019)]

foresight   new study methods to track and understand how major trends and technologies could shape our future – how to prepare for different futures in an uncertain world (European Union, 2020)

framework conditions   external: all external socio-economic aspects that shape the external environment (e.g. market, politics, law and regulations as well as society)

internal: all external socio-economic aspects that shape a company's environment. Those are market, politics, law and regulations as well as society

Source: (Wedel and Ulbrich, 2021)

governance   the actions and policies employed to effectively manage the crowd and steer them toward the desired solution (Pedersen et al., 2013)

One Health   the collaborative efforts of multiple disciplines working locally, nationally, and globally, to attain optimal health for people, animals, and our environment (American Veterinary Medical Association and Force, 2008)

OH emphasizes the commonalities of human, animal, plant, and environmental health. In this perspective, it can be regarded as an 'umbrella' term that captures integrative approaches to health across these highly interlinked components [see Rüegg et al. (2018)]

prototype   representation of all or part of an interactive system, that, although limited in some way, can be used for analysis, design and evaluation [see ISO (2019)]

resilience   adaptability of a system upon disturbances to allow it to recover and remain sustainable [see Rüegg et al. (2018)]

Responsible Research and Innovation	an approach that anticipates and assesses potential implications and societal expectations with regard to research and innovation, with the aim to foster the design of inclusive and sustainable research and innovation; societal actors (researchers, citizens, policymakers, business, third sector organisations, etc.) work together during the whole research and innovation process in order to better align both the process and its outcomes with the values, needs and expectations of society
	Note: In practice, RRI is implemented as a package that includes the five fields a) multi-actor engagement; b) open access, c) gender, inclusiveness and social equality in science, d) research ethics and integrity and e) formal, informal and non-formal science education (European Commission[13])
satisfaction	extent to which the user's physical, cognitive and emotional responses that result from the use of a system, product or service meet the user's needs and expectations [see ISO (2019)]
sector	an area of activity aimed at benefits to society, characterised by common processes and institutions. Examples include health, agriculture, transportation, education and environment [see Rüegg et al. (2018)]
stakeholder	groups or individuals, who are influenced by an organisation or can influence an organisation (Ackermann and Eden, 2011)
	individual or organization having a right, share, claim or interest in a system or in its possession of characteristics that meet their needs and expectations [see ISO (2019)]
structure	systems of communication, systems of authority, and systems of workflow. It further includes both the normative dimension, that is, values, norms, and general role expectations, and the behavioural dimension, that is, the patterns of behaviour as actors communicate, exercise authority, or work within the internal crowd (Knop et al., 2017)
system	includes systems of communication, systems of authority, and systems of workflow. It further includes both the normative dimension, that is, values, norms, and general role expectations, and the behavioural dimension, that is, the patterns of behaviour as actors communicate, exercise authority, or work within the internal crowd
suggestion	a proposition (e.g. health-related topic, question, task, information need) or offer (e.g. present, teach, engage, ….)
sustainability	the continuation of benefits from an intervention. The probability of continued long-term benefits. The resilience to risk of the net benefit [see Rüegg et al. (2018)]
task	an activity that is accomplished within a defined period of time or terminated with a deadline [see Rüegg et al. (2018)]
team	a group of individuals who work together to produce products or deliver services for which they are mutually accountable. Team members share goals and are mutually held accountable for meeting them, they are interdependent in their accomplishment, and they affect the results through their interactions with one another. Because the team is held collectively accountable, the work of integrating with one another is included among the responsibilities of each member [see Rüegg et al. (2018)]
topic	an overarching topic, which can lead to suggestions, tasks or challenges [see ISO (2019)]
usability	extent to which a system, product or service can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use [see ISO (2019)]
user	an individual, who chose to register on the JoinUs4Health platform
	active user: user, who actively engages with the project, i.e. invests time (generally) on a voluntary basis to address tasks or contribute to teams

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[13] https://ec.europa.eu/programmes/horizon2020/en/h2020-section/responsible-research-innovation#Article

	passive user: user, who uses generated outputs and possibly also engages in passive and governing voting
user experience	user's perceptions and responses that result from the use and/or anticipated use of a system, product or service [see ISO (2019)]
user interface	all components of an interactive system (software or hardware) that provide information and controls for the user to accomplish specific tasks with the interactive system [see ISO (2019)]
visitor	an individual, who is not registered on the platform, but explores outputs via the JoinUs4Health website or open access area of its platform