EUROPEAN
POLICYBRIEF

JOIN US TO OPTIMIZE HEALTH THROUGH COHORT RESEARCH

JoinUs4Health merges crowdsourcing and Responsible Innovation as converging approaches. Our online platform enables different scales of collaboration and connects consultative mechanisms with deeper cocreation processes in smaller teams. Three cohort institutions act as living labs to test the concept under different settings.

30 June 2022

INTRODUCTION

Institutional changes are required to respond to the increased interactions between Research and Innovation (R&I) stakeholders in society. Through institutional changes, research funding and performing organisations become more "porous" and accept inputs from citizens and organisations that used to be considered outsiders to the world of R&I. Examples include citizen science, extended peer review in funding agencies, co-creation of public policies, agenda setting in research and innovation programmes, co-production of research and innovation content, co-design of R&I programmes, and co-evaluation of proposals, activities or other R&I funding decisions.

Good practices are widespread in Europe in terms of citizens' and citizens' associations engagement in science; formal, informal and non-formal science education"; gender equality in science; research ethics and integrity; open access to research results including data. The good practices in these five fields are much more easily, efficiently and sustainably implemented when the organisations funding, performing or associated to R&I have adapted significantly their governance frameworks to open up through a process of institutional change.

Results should contribute to a greater involvement of all stakeholders in R&I, a better and more sustainable engagement with citizens and society as a whole, and a more scientifically interested and literate society. It is expected that the topic will support a significant number of impactful and sustainable institutional changes in partner organisations. Consortia are expected to evaluate their activities and provide evidence of societal, democratic, economic and scientific impacts of institutional changes.

JoinUs4Health is developing crowdsourcing as a concrete tool for participatory and responsible research. Our ambition is to engage cohort participants, citizens and other groups of societal actors in the cohort regions and beyond in a more co-creative manner, so as to make cohort research more sensitive to societal expectations and concerns and to promote inclusive engagement.

The JoinUs4Health consortium includes three cohort institutions in Germany, Poland and the Netherlands (Table 1). As part of the cohorts, one or more groups of randomly selected individuals are examined at baseline and then re-examined at approximately five-year intervals. To date more than 28,000 participants have been enrolled and followed over time for up to three decades. We will explore how we can leverage the strengths of each institution and value differences between them to understand how context (e.g. organisational, cultural) can shape the implementation of our methodology.

Table 1. Institutional changes focus on the three cohort partners of JoinUs4Health.

	Cohort project	Cohort	Begin	Number of participants*
🇩🇪	Study of Health in Pomerania (SHIP)	START	1997	4,308
		TREND	2003	4,420
		NEXT	2021	~ 800 [4,400]
🇵🇱	Bialystok PLUS		2018	~ 1,300 [10,000]
🇳🇱	Rotterdam Study	RS-I	1989	7,983
		RS-II	1999	3,011
		RS-III	2006	3,932
		RS-IV	2016	3,006
Total				>28,000

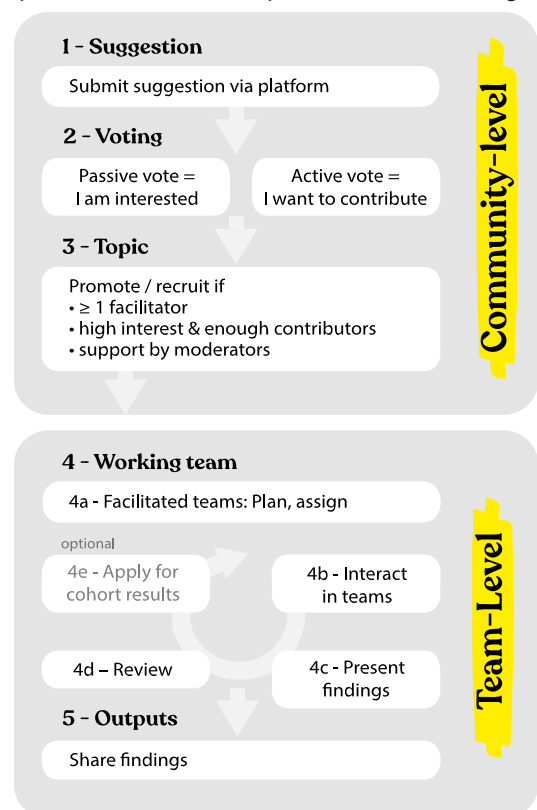* Square brackets: Target number (recruitment ongoing)

Our online platform 1 allows registered users to act as crowd sourcer or crowd member (Figure 1): They can submit suggestions (e.g. research question or information need; Step 1) and promote suggestions of others by voting (Step 2), commenting or expressing willingness to contribute time. A topic (Step 3) may lead to team-level interactions (Step 4). Teams can post tasks to the community (blue double arrow) and apply for customized cohort results to support their interactions (Step 4e; IC4). Summaries are regularly posted (Step 5) to foster cross-fertilisation.

The concept includes some key requirements: 1) all contributions at the community-level (suggestions, comments) are reviewed prior to being posted (no open forum) and 2) interactions (teams, tasks) can only start if at least one facilitator (any user) and a moderator with R&I background (supervisor) agree to coordinate the overarching topic. Furthermore, two advisory boards with members from different stakeholder groups

Six institutional changes (ICs) are implemented at the cohort institutions:
- engagement of citizens and other groups (IC1)
- fostering of R&I mentality (IC2)
- targeted communication of cohort results (IC3)
- semi-open access to cohort data (IC4)
- independent advisory board (IC5)
- integration of R&I in education (IC6)

Figure 1. Core steps of the JoinUs4Health platform to facilitate responsible crowdsourcing

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¹ https://platform.joinus4health.eu/
² Roundtable discussion at the Engaging Citizen Science conference in Denmark (25-26 April 2022); Open Innovation in Science (OIS) Research Conference 2022 in Austria (11-13 May 2022); 4th Session of the Cross-SwafS Stakeholder Forum for Responsible Open Science (7 April 2022)

support decision-making and provide strategic oversight in each cohort region (IC5). We discussed our concept at three international meetings 2 and at the 2 nd annual meeting of oursupport decision--making and provide strategic oversight in each cohort region (IC5). We discussed our concept at three international meetings 2 and at the 2 nd annual meeting of our international RI advisory panel. These exchanges provided important insights from a range of perspectives.

Now we are moving from the theoretical design to the practical implementation phase of the project. In the upcoming months, we will organize a range of events to help build the JoinUs4Health online community including press releases, a podcast, research cafés, engagement of pupils (Junior Medical School), undergraduate students (Minor From Science to Society) and virtual meetings with citizens, public health authorities and other groups. Simon Ruegg (University of Zurich) facilitated the first out of three evaluation workshops to co-create the Theory of Change, which will be used to assess the impact of the project in the local communities.

<div style="background:green;color:white;padding:8px;font-weight:bold">POLICY IMPLICATIONS AND RECOMMENDATIONS</div>

- **Cohorts:** The cohorts provide a valuable practical example of applying the concept as they can contribute local expertise, access to cohort results and networks. The concept is however considered to be also applicable in other settings

- **R&I:** Crowdsourcing offers a concrete methodological tool to implement R&I. Although currently R&I is sometimes replaced with "open science", the basic ethos is still in place: to strengthen trust in science and to make research relevant and sensitive to societal needs and concerns, we must open up the research process, but in a responsible manner. In other words, open science should be "open and responsible science". This means that crowdsourcing platforms must be managed in a responsible manner to foster dialogue, respect and epistemic inclusion (responsible crowdsourcing) rather than polarisation

- **Crowdsourcing:** Our platform combines consultative mechanisms typical of crowdsourcing with deeper team-level interactions. The concept strives to provide a controlled online environment (review, facilitator), strategic oversight (moderator, project partners, advisory boards) and guidance on R&I. The aim is to generate more tangible benefits for society by nurturing transdisciplinarity, innovation, cross-fertilization and diversity at the team- and platform-level

- **Time:** The idea of R&I is not widespread and understood in the cohort regions. The implementation of R&Ibased solutions requires time to build awareness and promote the importance of these solutions at the cohort institutions and in the local communities

- **Education:** Deliverable 5.2 provides recommendations for policy makers and educators to implement R&I in universities and educational institutions. Figure 2 summarizes our findings including recommendations (inside the circle) linked to the project providing the recommendation(s) (outside the circle). When implementing R&I elements within an organization, policy makers are advised to start working on one problem at a time (centre of the white circle). A good starting point is the self-reflection process followed by planning actions together with a dedicated team. Developing guidelines, providing incentives, changing curricula and making use of external changes and trends may help accelerate the process of change (outer part of the white circle). To achieve this, it is important to consider the topics that are presented in the blue circle

- **Perspective:** We believe that implementing R&I in our organizations is a logical next step to the already ongoing initiatives in our organizations
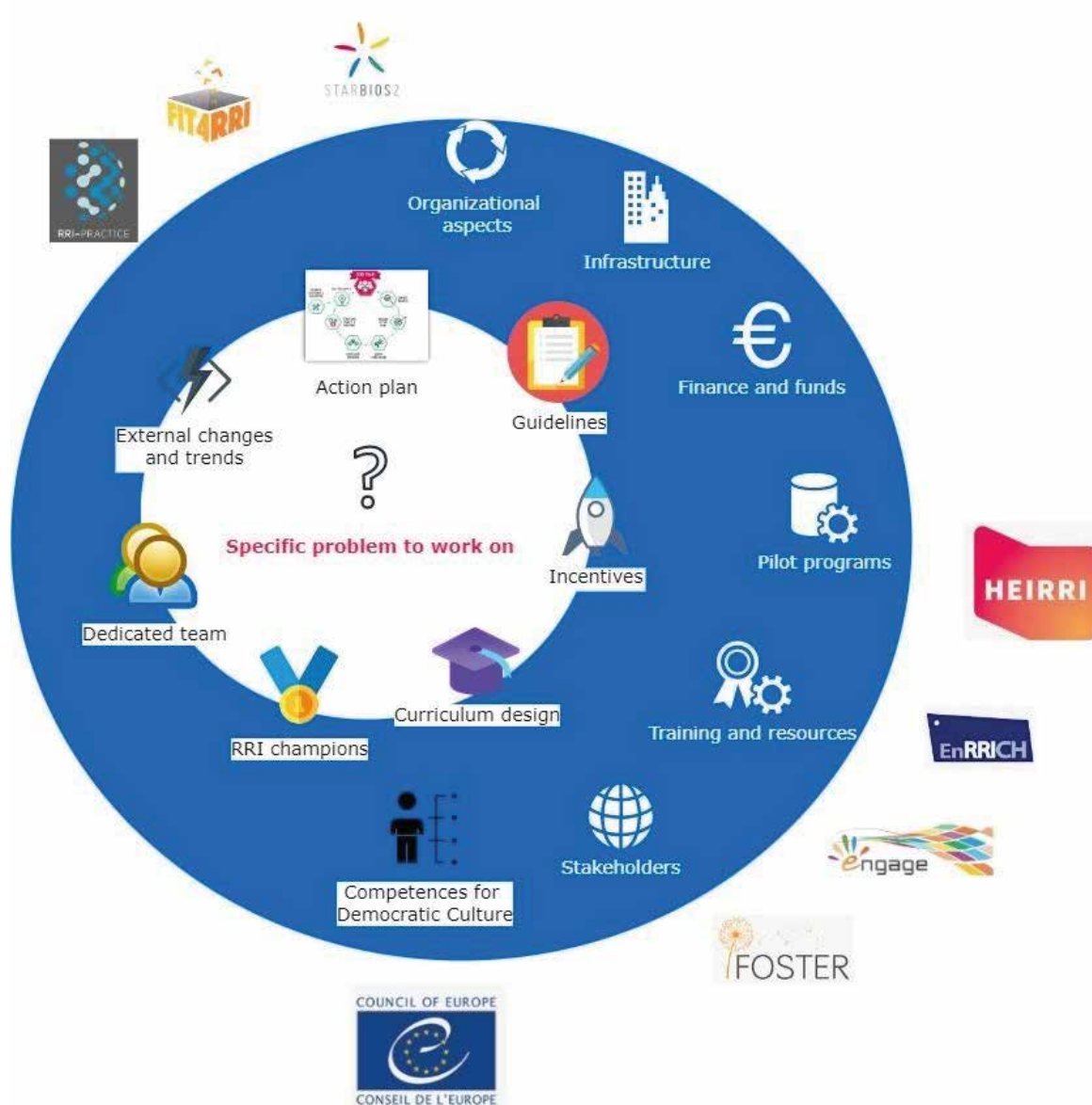
Figure 2. Recommendations for policy makers and educators to integrate R&I in universities and educational institutions (source: Deliverable 5.2)

SUSTAINABILITY AND LEGACY

- The platform will be accessible until at least December 2026

- In August-September 2022, we launch the Minor From Science to Society (**IC6**) at the Erasmus University of Rotterdam. As part of this brand new 10week educational period for bachelor students, R&I principles and the field of open science are introduced in an interactive way. Students tackle societal problems from different R&I perspectives and engage stakeholders, including but not limited to stakeholders within Civil Science Organizations, Business and Industry and Policymaking. It is our ambition to leverage and learn from these insights to expand on this minor in coming years, and ultimately to grow it to a Bachelor or Master program for students at the university level. For more information, please have a look at this video, visit Minor From Science to Society | Erasmus University Rotterdam or email one of the minor coordinators (s.licher@erasmusmc.nl or n.terzikhan@erasmusmc.nl)

Project objectives are:

1) ESTABLISH and REVIEW a conceptual framework
2) DEVELOP, TEST and APPLY technology to engage various societal actors
3) EXPLORE, IMPLEMENT and MONITOR institutional changes and incorporate R&I into the governance framework of three cohort institutions
4) ADVANCE R&I and citizen science into the mainstream of public engagement, science communication and education
5) PROMOTE engagement and COMMUNICATE and DISSEMINATE outputs via traditional and innovative means

Now that the online-platform is released, the JoinUs4Health project is entering the mobilization phase to engage citizens, scientists, policy makers and representatives from the education community and business / industry. Hence, the focus will shift from objectives 1 and 2 to objectives 3, 4 and 5. During the 2nd project phase we will aim to deepen exchanges with other SwafS projects to benefit from each others' perspectives and experiences.

The online platform may act as a boundary object that connects different stakeholder communities under a shared purpose and allows coordination of action without necessarily striving for consensus among those groups and consequently overlooking the perspectives of specific actors. We expect that the JoinUs4Health platform can inform activities at the cohort institutions such as adaptions of curricula and enhanced application of R&I methods and approaches.

The impact of this project can be manifold. Besides democratizing science (suggest, vote), leveraging innovation potential and increasing societal relevance of cohort research, we hypothesize that generating more tangible benefits for (local) societies might have a positive effect on cohort response in these study regions. An increase in cohort response would provide a convincing argument for cohort institutions to embrace R&I as an institutional vision.

PROJECT IDENTITY

PROJECT NAME

Join Us to Optimize Health Through Cohort Research (JoinUs4Health)

COORDINATOR

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CONSORTIUM

Erasmus University Rotterdam – EUR – Rotterdam , Netherlands
Medical University Bialystok – MUB – Bialystok, Poland
Erasmus Medical Centre – ERASMUS MC – Rotterdam, Netherlands
University of Bialystok – UwB – Bialystok, Poland
White Bits, Bialystok, Poland
Akademie for Public Health – AkademieÖGW – Düsseldorf, Germany
Foundation Laboratory of Research and Social Actions – SocLab – Bialystok, Poland
Science4People, Bialystok, Poland
The Netherlands Patient Federation – NPF – Utrecht, Netherlands
Mijn Data Onze Gezondheid – MDOG – Amsterdam, Netherlands

FUNDING SCHEME

Horizon 2020: SwafS-23-2020 Grounding R&I in society with a focus on citizen science

DURATION

January 2021 – December 2023 (36 months)

BUDGET

EU contribution: 1 588 541 €

WEBSITE

www.joinus4health.eu

FOR MORE INFORMATION

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FURTHER READING

- Birgit Schauer (2018): "Crowd sourcing to bridge the gap between science and public health", MOJ Public Health, 7, 189-190 (Link)
- Hub Zwart and Birgit Schauer (2021): "Deliverable 2.1 Methodological guidelines on implementing R&I and crowdsourcing in cohort research for partners", Erasmus University of Rotterdam, Rotterdam (Link)
- Ana Barbosa Mendes, Silvan Licher et al (2022): "Fostering organizational learning through responsible crowdsourcing in prospective cohort studies", OSF Preprints (Link)
- Natalie Terzikhan, Ana Barbosa Mendes et al (2022): "Deliverable 5.2: Published recommendations for policy makers and educators to integrate R&I in universities and educational institutions", Erasmus Medical Centre (Link)
- Henry Völzke, Janka Schössow et al (2022): "Cohort profile update: The Study of Health in Pomerania (SHIP)", International Journal of Epidemiology, 1–12 (Link)