



EUROPEAN POLICYBRIEF



JOIN US TO OPTIMIZE HEALTH THROUGH COHORT RESEARCH

The second JoinUs4Health policy brief provides recommendations based on overall results of the project, with particular emphasis on how to improve the effectiveness of combining crowdsourcing and Responsible Research and Innovation (RRI) methodologies as converging approaches in the field of cohort research. The three medical cohort institutions (EMC, MUB and UMG) and their RRI mentoring partner (EUR) share experiences and visions to achieve social changes through cohort research, which provide the foundation for the project's sustainability and effectiveness.

31 December 2023

INTRODUCTION

Institutional changes are required to respond to the increased interactions between 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.

Crowdsourcing was promoted as a valuable tool for EU policy making following a consultative exercise in ten European cities (1). Between 01/22 and 01/23, the European Citizen Action Service (ECAS) provided an online platform, which allowed citizens to propose solutions on how to improve air quality and vote on others' suggestions with the most favoured ones being presented to policy makers. The JoinUs4Health concept was designed to do that and more by allowing contributors to also work together in a secure environment (virtual meeting room, chat function, joint editing of documents). A key incentive is the option to apply for results from three cohort studies, which have examined over 30,000 participants to date in approximately five-year intervals.

The aim of JoinUs4Health is to combine crowdsourcing and RRI as converging approaches to promote citizen engagement and innovation in cohort research. Geographically, the project focusses on the study regions of the three population-based cohort studies: the Study of Health in Pomerania (SHIP) in Northeast Germany since 1997 (2), the Rotterdam Study in the Netherlands since 1989 (3) and Bialystok PLUS in Poland since 2018 (4). The three cohort institutions implemented six institutional changes in the following areas:

- Engagement of citizens and other societal actors via on- and offline activities
- Semi-open access to cohort data tailored to the topic of interest
- Targeted communication and dissemination of results
- Citizen science boards comprised of different stakeholder groups
- Implementation of RRI in the cohort institutions
- Education

The underlying crowdsourcing concept was to be implemented primarily via online activities. The JoinUs4Health platform (released in April 2022) may act as a virtual science shop, a place where anyone from the age of 16 can submit suggestions, vote on others' contributions or work with others on health-related topics via tasks or teams (Figure 1). The potential of JoinUs4Health was widely discussed at the Towards Comprehensive Population Studies II Conference (4–6) and at the Citizen Science Week in Bialystok, which focused on healthy cities. Numerous offline events promoting RRI took place in Bialystok: Research Café, workshops for researchers and non-governmental organizations, Youth City Council. These offline activities were most effective in generating traffic on the platform and also contributed to other youth initiatives (e.g. recommendations for the prevention of mental disorders in schools).

The concept remains to be fully tested as community building is ongoing. But we have learnt a lot in the process through a range of online and offline activities targeting different stakeholder groups. EMC has focussed on education and achieved highly sustainable and impactful achievements (10-week Minor Programme "From Science to Society", which received the 2023 EUR Open and responsible Science award; integration of RRI in the medical curriculum). Educational activities were also carried out in Bialystok. In Germany, four workshops were organized with representatives from public health authorities amongst other activities.

Please refer to our deliverables for summaries of methodological reflections (Deliverable (D) 2.2 and D2.3), platform implementation (D3.1), institutional changes (D4.3), education activities (D5.4 and D5.5), communication, dissemination and engagement activities (Deliverable 6.7) and evaluation (D7.3-D7.5).

Karol Kaminski, leader of the Bialystok PLUS cohort, summarized experiences as follows (4): "We thought we will have a place, where citizens will come and then they will contribute. In fact, it is hard work to encourage people to participate. Those actors and facilitator are needed, and that needs funding. We need an attitude amongst scientists to appreciate the value of openness. Then we need people to promote the knowledge transfer, enriching the population. But it must be bidirectional. Citizens need to be activated to actively participate in science."

Outlook: The geographical link to the cohort regions and semi-open access to in-depth cohort data provides tremendous potential to combine local scientific and societal knowledge to work on integrated health approaches tailored to local settings. Currently, it is still too early to see a measurable impact, e.g. in terms of a more scientifically interested and literate society. The institutional changes are however showing first effects and will be sustained beyond the project period as expressed by cohort leaders of EMC (5,6) and MUB (4).

POLICY IMPLICATIONS AND RECOMMENDATIONS

- RRI is a new way of working. Although RRI has been promoted for over 10 years, it initially appears complex.
- The online platform can support RRI 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.
- At the institutional level, RRI requires an ongoing interaction between specific activities. Structural changes need to happen at different levels (research, infrastructure, education, ...) to foster responsible research in the long-term (D2.3).
- Considerable investment of time and effort is required (4) to
 - promote a change in mindset amongst scientists and citizens to appreciate the value of RRI as a new way of working
 - encourage people to participate, build relationships, sit down and talk with citizens and stakeholders. “We cannot expect people to come to us” (6).
- “RRI champions” within institutions are highly effective in creating a sustained change in institutional mindset and should therefore be promoted in as many areas as possible (6).

General recommendations when embarking on the process of institutional change (see D2.3):

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

SUSTAINABILITY AND LEGACY

JoinUs4Health platform (<https://platform.joinus4health.eu/>) with 263 registered users, 54 suggestions and 16 topics to date (see D7.5 for detailed overview of Topic and Suggestion contents). The platform infrastructure is open source (<https://github.com/JoinUs4Health>). A range of education materials and podcasts are listed with links in D7.3. Project outputs are also available on our project website (www.joinus4health.eu) and/or Zenodo (<https://zenodo.org/communities/joinus4health>).

PROJECT OBJECTIVES AND METHODOLOGIES

Epidemiology is the only way to investigate the causes of disease in the intact human being. The three participating cohort institutions (EMC, MUB and UMG) have generated large and in-depth databases by following groups of randomly selected individuals ('cohorts') over time (participating cohorts: in approximately five-year intervals).

The JoinUs4Health project objectives are to:

- 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 RRI into the governance framework of three cohort institutions
- 4) ADVANCE RRI 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

The JoinUs4Health platform allows anybody from the age of 16 to submit suggestions (Step 1), vote on others' contributions (Step 2) or work with others on health-related topics via tasks or teams (Step 4; Figure 1). Teams have the opportunity to apply for cohort results tailored to their topic of interest (Step 4a). A requirement for a topic to be promoted via the platform (Step 3) is that at least one platform user (no experience required) volunteers as facilitator, acting as main contact person for contributors. The facilitator is teamed up with a moderator who has experience with RRI and takes on a mentoring role.

Platform contents and various project materials (deliverables, lesson plans, podcasts, education materials, etc.) are open access. The platform is open source.

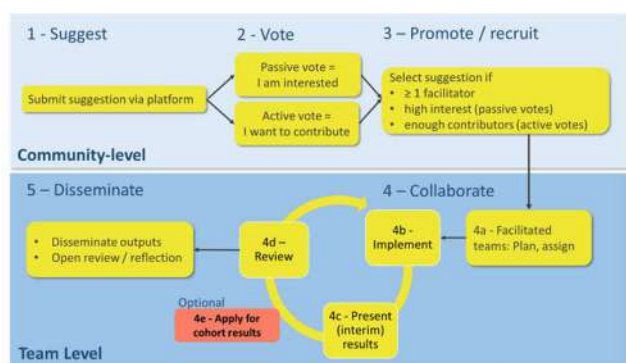


Figure 1. Core steps of the JoinUs4Health crowdsourcing concept

PROJECT IDENTITY

PROJECT NAME	Join Us to Optimize Health Through Cohort Research (JoinUs4Health)
COORDINATOR	Dr. Birgit Schauer, University Medicine Greifswald (UMG), Greifswald, Germany (birgit.schauer@uni-greifswald.de)
CONSORTIUM	University Medicine Greifswald – UMG – Greifswald, Germany 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 RRI 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	Natalie Terzikhan (n.terzikhan@erasmusmc.nl) or Pawel Sowa (pawel.sowa@umb.edu.pl)
FURTHER READING	<ul style="list-style-type: none">• Mendes AB, Licher S et al. Fostering organizational learning through responsible crowdsourcing in prospective cohort studies [Internet]. Pre-print available on OSF Preprints. 2022: https://osf.io/preprints/osf/t47yh• Deliverable 2.3: Factors affecting engagement and uptake of RRI in cohort research• Deliverable 4.3: Evaluation report on implemented institutional changes• Deliverable 5.5: Reports on the engagement of citizens in (online) scientific courses, and contributions of high school and students in scientific research• Deliverable 7.3: Final monitoring and evaluation report

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