



## Join Us to Optimize Health Through Cohort Research

Deliverable 5.5: Reports on the engagement of citizens in (online) scientific courses, and contributions of high school students in scientific research

Version 1.0

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### List of Abbreviations

PPL	Problem-based Project Learning
RRI	Responsible Research and Innovation
WP	Work Package

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## Summary

This report concerns Deliverable 5.5 of the JoinUs4Health project (grant number 101006518). As leaders of the Work Package (WP) “Formal and informal education”, we provide a summary of undertaken activities and reports in relation to the engagement of citizens in (online) scientific courses, and contributions of high school pupils and students in scientific research. In this report, we also reflect and review the impact of these activities on the sustainability of the concept of JoinUs4Health.

## Introduction

In this deliverable (D5.5), we present our current formal and informal educational activities, through which the Responsible Research and Innovation (RRI) concept is shared at our workplace, the Department of Epidemiology of the Erasmus Medical Centre in Rotterdam – The Netherlands. This deliverable serves as a step -up for Deliverable 5.4, in which we elaborate and zoom in more on selected educational activities, as mentioned in the summary here. In Deliverable 5.4, we for instance highlight developed resources and educational materials of two RRI informed projects, the 10-week **From Science to Society** RRI course, and the **What the Health** podcast series. Together, Deliverables 5.4 and 5.5 form the backbone of our work in WP 5 on formal and informal education. Activities are designed to foster RRI through education and make the designed material publicly available to a broader audience.

In this deliverable, we outline activities that have been carried out to teach and practice RRI in three different formats:

- 1) By directly teaching the concept of RRI formally;
- 2) Advocating for RRI at an institutional level by indirectly teaching RRI; and finally
- 3) By formally and informally practicing RRI ('practice what you preach').

In the upcoming chapters, we will highlight the background and activities for each of these three formats.

## 1. Direct and formally teaching the concept of RRI

### **A 10-week RRI course for bachelor students ‘From Science to Society’**

As extensively described in Deliverable 5.4, we have successfully developed and implemented a 10-week RRI course for bachelor students ‘[From Science to Society](#)’. This minor has caused some disruptive change at the Erasmus University Rotterdam, since it has been open for students from all faculties, and it has been designed according to principles of Problem-based Project Learning (PPL). Through evaluation with students and teachers over the past two years, we have learned that these characteristics have resulted in very diverse and welcome set of bachelor students that enrolled in this minor, ranging from medical students to those that study history and arts. Similarly, teaching the program according to PPL principles resulted in larger feelings of learning autonomy than usually experienced by the enrolled students from their original faculties. In eight weeks, groups of five to six students worked together on a societally relevant topic and engaged relevant stakeholders from the beginning onwards. At the end of the course, students presented their findings to the engaged and other societal stakeholders during a plenary symposium.

### **Junior Medical School (JMS)**

In addition to involvement in the regular curriculum of the Erasmus MC, we also actively involved high school students in the JoinUs4Health project. In 2021 and 2022, we supervised students during the summer holiday break of their high schools in conducting scientific research. We invited them to the JoinUs4Health platform to actively engage with other societal stakeholders, and to present their (interim-)findings to a broader audience. They, for instance, worked on a project that studied time trends in healthcare avoidance during the COVID-19 pandemic in the general population. The interactive discussions resulted that two of our students received the prestigious Gerrit-Jan Mulder award for societal impact [Gerrit Jan Mulder Stichting - Erasmus MC](#). The students subsequently enrolled in the Medical Curriculum of the Erasmus MC.

## 2. Advocating for RRI at an institutional level by indirectly teaching RRI

In addition to formally teaching the concept of RRI, we have extended our input and activities to adjacent developments, ensuring that awareness and implementation of RRI concepts are also increasingly acquired at an institutional level. This undertaking has resulted in a significant impact and change at the institutional level of the Erasmus MC. It for instance 1) led to an adaption to the structure and organization of the new medical curriculum of the ErasmusMC, ErasmusArts2030, and 2) boosted the rethinking of institutional recognition system for researchers. In the next two paragraphs, we will further describe these institutional developments.

### **New Medical Curriculum Erasmus MC**

Erasmus MC is designing a new medical curriculum and recently defined a renewed vision '[Erasmusarts2030](#)': Erasmus MC wants to train students to become broad academically trained medical doctors who are well prepared for new technological developments and societally engaged. For that purpose, the new curriculum will develop and incorporate elective tracks in the Bachelor Erasmusarts2030, which will be continued in the Master. In four different thematic tracks, students learn to deal with health related issues through the lens of inclusivity, stakeholder engagement and societal relevance. These thematic tracks are an entirely new feature of our curriculum and will enable students to work on societal and health(care) problems of their own choice together with different stakeholders, including citizens, patients, teachers and students from other faculties as well as business partners. We from the JoinUs4Health consortium had a prominent role in designing these tracks, and advising on the best way to provide a large number of students (400) with this type of teaching, through small pilots. After consultation with educational experts, we decided to implement the educational framework of a problem-based project in these tracks, which asks for a different role of teachers as supervisors as well as of students, but also asks for a different organization of education. Given that each year 410 students enrol in our Bachelor of Medicine, it is of utmost importance that these tracks are carefully developed, designed, and (at least partly) tested before the start of the new curriculum in 23/24. The JoinUs4Health consortium provided the ideal circumstances to accurately test several of these tracks during the period duration of three years. In these pilots of problem-based project learning, we offered our students new skills (e.g., how to critically analyse a real-life health related societal problem, how to manage a project, how to collaborate with peers, etc.) and how to gain (societal) impact. In addition, our pilot teachers provided insights on the role of teachers as project managers. Lastly, the JoinUs4Health project not only informed the development of the thematic

tracks for the new Bachelor of ErasmusArts2030it also advised other initiatives that were concerned with implementing problem-based project learning at their institutions including Impact@theCore and cross-university collaborations including UNIC.

## **Rethinking the recognition systems for academic researchers**

Over the years, the reward system for academic researchers has undergone significant changes. To tackle growing societal challenges, a shift towards more responsive and responsible knowledge production is imperative. In line with the European Commission's lead, we actively advocate for this change and warmly embrace this shift within the department of Epidemiology. We therefore strive not only to work towards these new European standards, but also to accord with National standards for Recognizing and Rewarding academic scientists and output (= Erkennen & [Waarderen](#)) as well as [Open Science](#) (open data, methods, infrastructure, and education) and Responsible Research and Innovation (anticipation, inclusion, reflexivity, and responsiveness) principles.

The JoinUs4Health consortium has significantly contributed to these changes in the following ways. First, we have now upgraded our focus from informal to formal and structural support for RRI and responsible research within our department. We have set up a dedicated research line, 'Responsible Research' at the heart of the department of Epidemiology, led by Natalie Terzikhan. Second, our department contributed to an institutional pilot program to reward departments from the Erasmus MC differently than has previously been done. In this new narrative format, academic staff describe department strategy in terms of goals and milestones, and also focuses on more qualitative and inclusive indicators of success. The JoinUs4Health substantiated this evolution as we actively build-up expertise and infrastructure for RRI and Open Science over the past three years. More specifically, one of the key statements in the contemporary mission of the department relates to the promotion and maintenance of societal engagement by adopting Recognition and Rewards, Open Science and Responsible Research and Innovation (RRI) principles. In the department, we operationalize RRI through several key positions of our staff in various research, education, and outreach communities at the institutional, regional, national, and international levels. Moreover, we pay special attention to research integrity and facilitating open, diverse and inclusive science. This also closely aligns with the Erasmus MC Strategic Focus Area within the Research Strategy of the Erasmus MC, which also promotes collective stewardship of science and innovation by adopting principles of Recognition and Rewards, Open Science and Responsible Research and Innovation.

### 3. Formal and informal practice of RRI ('practice what you preach')

Beyond our more 'formal' activities to teach RRI, we also set out activities to learn, teach and practice RRI in a more informal way. The JoinUs4Health consortium provided momentum to start interactive ways to engage citizens, patients and other societal stakeholders in our research that was formerly more driven from a research perspective.

#### **Rotterdam Study Webinars**

Over the years, we have used our international collaborations and experience to broaden patient engagement in cohort research. Leveraging actual topics, such as the COVID-19 pandemic, we have built expertise and set up infrastructure to host and organize webinars that are open for participants of an ongoing cohort study, as well as for the general public. On December 27, 2021, we hosted our first webinar 'COVID-19 Research in the Rotterdam Study: from ideas to results'. We followed up on this webinar on April 17, 2023 with a second edition entitled 'Out of the pandemic: what did the Rotterdam Study bring us?' Both of these webinars were well attended, and are available freely online ([Uit de pandemie, wat heeft ERGO ons geleerd? - YouTube: https://www.youtube.com/watch?v=DDN2jBB9oME](https://www.youtube.com/watch?v=DDN2jBB9oME)).

#### **Citizen Science Council ('Burgerraad voor Wetenschap')**

In line with the consortium ambitions, we have set up a dedicated Citizen Science Council, consisting of patients, researchers, implementation experts and participants of the Rotterdam Study. This multidisciplinary council has been designed to include all relevant stakeholders from study conception to implementation of final results to (clinical) practice. The council has had regular (online) meetings, in which we discussed progress of the JoinUs4Health initiative, ongoing research projects, and brainstormed about new ideas from societal stakeholders for scientific projects. The council faces a challenge regarding its sustainability due to the constant turnover of members. Its current state is too nascent to persist without ongoing support from JoinUs4Health staff members. Therefore, we aim to integrate and connect the council with parallel initiatives at both local and national levels, such as the participant board of the Rotterdam Study and the patient panel from the Dutch Patient Federation, respectively.

#### **A practical example of the *sustainable* impact of the JoinUs4Health consortium**

In parallel with ongoing activities, we also direct our focus on the horizon and the role of the JoinUs4Health concept and its platform in other future research activities. We have been invited

by the Dutch Research Council (NOW) to participate in a national center for expertise to study Post-COVID sequela <https://www.rijksoverheid.nl/actueel/nieuws/2023/06/01/ruim-%E2%82%AC32-miljoen-extra-voor-onderzoeksprogramma-en-nationaal-expertisenetwerk-post-covid> In that position, we are actively contributing to design and set up a national platform for patient participation in research, dissemination and implementation of this consortium. The JoinUs4Health experience, infrastructure and network serves as a motivating example in this new consortium to guide researchers, patients and representatives in successfully setting up a national hub for patient engagement and contribution in scientific research. Currently, these activities are still in early stages of development, yet it already demonstrates the significant value and (international) recognition of the JoinUs4Health consortium in setting up and organizing patient engagement in scientific research according to RRI principles. We strive to use the JoinUs4Health platform, or alternatively link it towards existing and ongoing research initiatives at our institution to maintain its useful utilities sustainably.

## Discussion

Over the past three years, the JoinUs4Health project has led to significant developments to advance RRI thinking at various levels, including departmental (dept. of Epidemiology, institutional (Erasmus MC) and national (i.e., National Expert center for Post COVID research and care). In this discussion section, we will reflect on our progress in engaging citizens in (online) scientific courses, and contributions of high school and students in scientific research. We will conclude with some plans and directions to further advocate for and work on RRI centeredness in scientific research and daily practice.

### **Reflections on the institutional dimension of RRI and the engagement of societal stakeholders in courses and research**

In D2.3 we argued that, although RRI is about reaching out to society, the internal or institutional dimension of RRI is crucial to make it work. RRI aspires to realize significant changes in the way in which research and education are being conducted, making academic research and teaching more responsive and interactive towards society. For this reason, RRI should not be seen as something extra, which is added to the already heavy workload of academics, but rather as an inherent part of academic work. In other words, research and teaching as such should become participatory processes to make them more open to society and sensitive to societal values and concerns. This also means that RRI (as an innovative, time-consuming process) should be acknowledged and rewarded (should become part of academic mechanisms for acknowledgement and reward). D5.5 concretely what this involves in practice, so that our example may serve as a model for others in the context of mutual learning.

Against that background, we distill the following three pillars for success after three years of building towards engagement of societal stakeholders in scientific courses and research.

### **Engaging citizens and students in Scientific Courses**

- **Accessibility and Inclusivity:** (online) scientific courses, like the 10-week Minor course, offer a unique opportunity to engage citizens and students from diverse backgrounds. By eliminating geographical and educational barriers, these courses can reach a broader audience, including those in underserved communities. An online platform alongside sustained funding to maintain such a platform is essential to ensure that these and future courses remain accessible and affordable to all.

- **Interactive Learning:** The effectiveness of these (online) courses depends on their interactivity. New funding opportunities remain critical to update and support the development of engaging and interactive course materials, simulations, and virtual laboratories, making the learning experience more hands-on and immersive.
- **Train the trainer:** High school and university teachers play a pivotal role in guiding students toward scientific courses. Additionally, we trained (former) students of the minor to become student assistants for new peers in the course. This enhanced the ability to facilitate (online) scientific education effectively.

### **Mentorship programs and research opportunities**

- **Mentorship Programs:** Encouraging high school students to participate in scientific research requires mentorship from experienced scientists. This is what we have done within the Junior Medical School program, and this infrastructure and expertise provides an ideal starting point to set these initiatives up in other initiatives. We will upload documentation of these mentoring programs to serve as a blueprint to inspire other interested researchers.
- **Research Opportunities:** Funding can be used to create research opportunities for high school students within academic institutions or research organizations. These opportunities can include summer research programs, internships, or partnerships with local universities.

### **Measuring impact and success**

- **Assessment Tools:** Developing assessment tools and metrics to measure the impact of online scientific courses and the contributions of high school students in research is crucial.
- **Long-Term Tracking:** Funding can be used to establish long-term tracking systems to monitor the progress and achievements of students who have participated in online courses and research programs. This data can be used to refine and improve future initiatives.

We conclude that engaging citizens in online scientific courses and involving high school students in scientific research are essential steps towards fostering a scientifically literate and empowered society. However, we do note that continuous support of staff personnel is essential to keep engagement and recruitment of new students or citizens active. Collectively working towards fund

applications is a next and crucial step in supporting these initiatives, ensuring that they are accessible, impactful, and sustainable. This is exactly the gap that the JoinUs4Health has probed to fill, and is, with its sustainable online platform where citizens, scholars and scientists can meet, perfectly fit for to work on in coming years. By investing in these programs, we not only enhance the quality of scientific education but also harness the potential of the next generation of scientists and researchers, paving the way for groundbreaking discoveries and advancements in various fields.

## Future directions

Although we are currently applying these principles, over the next years, our goal is to foster collective stewardship of science and innovation even more by:

1. Integrating a Recognition & Rewards position paper into our departmental policy: Diversifying and vitalizing career paths, focusing on quality over quantity, balanced promotion, and stimulating academic leadership and Open Science.
2. Prioritizing Open Science according to European and National (Dutch Research Council) endorsed pillars: FAIR/Open Access dissemination, Citizen Science, Diversity/Inclusion, and Recognition & Rewards principles.
3. Advocating, educating and advancing Open Science and Responsible Research and Innovation across the different departmental disciplines; management, research and educational activities.
4. Engaging and consolidating collaboration with different societal stakeholders.
5. Emphasizing the importance of research integrity and data security in all our activities, and prioritizing transparency and reproducibility in all published research. This includes ensuring that analysis code is openly accessible, results are shared transparently, and data is available where applicable, while taking into consideration any privacy concerns.