



Join Us to Optimize Health Through Cohort Research

Deliverable 4.3: Evaluation report on implemented institutional changes

Version 1.0

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Executive summary

This report presents a comprehensive evaluation of the institutional changes implemented by the JoinUs4Health consortium, following up on the activities described in Deliverables 4.1 and 4.2, which are published online at www.joinus4health.eu. The main objective of the project was the sustainable implementation of at least six key changes in the participating institutions. The analysis includes a discussion of both achievements and difficulties encountered during implementation in several areas, including responsible research and innovation (RRI), scientific skills, public engagement, open access, governance, and communication and dissemination.

It emphasises that achieving institutional change is a complex and multi-step process that often deviates from initial assumptions. The report highlights the successes as well as the challenges and obstacles that have affected the final outcomes. In particular, delays resulting from the need to integrate different approaches between research centres with different cultural backgrounds were clearly identified during the course of the project.

The evaluation shows that some institutional changes have not yet taken full effect, requiring adjustments in strategy and approach. The report also presents conclusions and recommendations for future action, including a proposal to extend the duration of the project in order to allow changes to be more fully implemented and evaluated.

The report's conclusions aim not only to evaluate past activities but also to provide guidance for future projects and initiatives, emphasising the importance of flexibility, continuous monitoring and adaptation in the process of institutional change. We, the authors, believe that this will be of the greatest value for the future development of RRI-related projects.

Open Access Policy and Public Data Dictionaries

1. Achievements

Data Dictionaries and Policy Comparison: it has been conducted an analysis and comparison of available data dictionaries and policies across various cohort studies, highlighting areas of strength and opportunities for improvement (see D4.2);

Coordinated development of resources in Bialystok PLUS cohort study: significant advancements were made in developing user-friendly data dictionaries and establishing a pipeline for data presentation that unfortunately has not been published on the JoinUs4Health platform yet (legal concerns reported by UMG);

Sensitivity to Data Openness: all cohorts involved have become more sensitive to data openness as a future direction for population-based research. The need to educate in this area, to integrate and harmonise data, and to look for ways to make better use of them in the future, was a recurring theme at the Towards Comprehensive Population Studies II conference in Bialystok (JoinUs4Health contexts appeared in 3 keynote presentations) and in complex deliverables (e.g. WP5);

Model Data Access Application Policy: developed a model data access application policy for the JoinUs4Health online platform in relation to individual cohort solutions (and its autonomy);

Data Pipeline Development for Local Community Engagement: developed a data pipeline (dashboard) to present important health issues for the local community (in Bialystok) - due to legal restrictions of the host provider (JoinUs4Health platform) it will be placed on the new Bialystok PLUS cohort study website currently being developed.

2. Impact of Proposed Institutional Changes

Standardization: The proposed changes aim to standardize formats and terminologies, which are crucial for enhancing data interoperability and user comprehension.

Enhanced Accessibility: By advocating for open access to data dictionaries, the project has taken a step towards promoting transparency and inclusivity in research.

3. Challenges and Considerations

Institutional Autonomy: The implementation of recommendations is subject to the decision-making processes of individual institutions, presenting a variability in adoption rates and extents. The JoinUs4Health experience shows that the decision on the data access policy with a catalogue of restrictions should always be in the autonomy of the respective cohort. Of course, the project has prepared a model solution, which we suggest to cohorts wishing to use

the JoinUs4Health online platform in the future as a potential form of collaboration with working groups forming online.

Resource Requirements: The development and maintenance of standardized, comprehensive data dictionaries require continuous effort and resources, which may be a constraint for some institutions. The Bialystok PLUS team has been awarded a grant from the Ministry of Science to develop a dashboard system to present collected data to different audiences (citizens, scientists, decision makers). This is a development of the data presentation pipeline concept prepared within JoinUs4Health

4. Recommendations for Future Projects

Strengthen Collaboration: Encourage a culture of sharing and collaboration among cohort studies, facilitating a more unified approach to data management and access.

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

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

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

5. Conclusion.

The process of enacting the Open Access policy and enhancing public data dictionaries in the JoinUs4Health cohort studies has presented both obstacles and triumphs. Although significant advancements have been made, there remains room for further development to unlock the full promise of these endeavors. Upcoming projects should consider the insights gained and embrace a versatile, cooperative, and encouraging strategy to cultivate a setting where data is not just reachable, but also clear and beneficial to an extensive array of participants. With ongoing dedication and creativity, we can anticipate a future of health research that is more transparent and welcoming. Unfortunately, due to the lack of such requests, it has not yet been possible to test the application model for team data access on the platform. However, it should be noted that a model framework has been developed for this purpose, which may provide valuable support for such requests in the future.

Governance and Advisory Bodies

1. Achievements

Establishment of Advisory Bodies in three countries: Notable success in creating advisory bodies with comprehensive bylaws and procedural rules has been instrumental in involving a diverse stakeholder group in governance.

Engagement and Collaboration: The regular interaction, communication, and cooperation among consortium partners and advisory boards members have significantly improved the initiative's efficacy, especially in Bialystok.

Beneficial Exchange of Experiences: The partnership with Bialystok, alongside Greifswald and Rotterdam, has led to a beneficial exchange of practices and experiences, enhancing the project's approach. It should be noted that they range from good to bad, but taken together they provide valuable know-how for the future work of these and similar bodies

2. Impact of Proposed Institutional Changes

Evaluation of Advisory Activities: In the upcoming months, the focus will shift to a thorough evaluation of the advisory bodies' activities, aiming for continuous improvement and adaptation. The evaluation, which was carried out in two phases: an internal exchange of experiences within the consortium and the collection of feedback from members of the advisory bodies (Citizen Science Board and Monitoring and Evaluation Group), enabled the identification of key factors that will increase the potential for effectiveness of such bodies in the future, as well as weaknesses. As highlighted in previous reports, slightly different recruitment and outreach strategies were adopted for potential members. In the case of Bialystok, this was the broadest representation of a cross-section of local society. It was also where the greatest number of meetings between the two groups took place. In Greifswald and Rotterdam, there is uncertainty at this stage about the future of these bodies, as the lack of staff and funding to maintain the groups appears to be a problem. The situation is different at the MUB, where it is planned to maintain the group by merging the two bodies into one and developing its role from an advisory one within the cohort study to a university-wide one and participation in the university's science policy.

Leveraging Lessons Learned: Insights from these evaluations will be crucial in refining the roles and operations of the advisory bodies, ensuring their sustained impact and relevance. They are described in detail in the Recommendations subsection.

3. Challenges and Considerations

Sustainability and Member Turnover: A key challenge is the sustainability of the advisory boards, in particular due to the constant turnover of members, which can affect the continuity and effectiveness of governance (all cohort partners reported that during the course of the project, due to the lack of activities on the platform and the lack or regularity of offline activities, the topics discussed by the boards were limited). Finding ways to maintain engagement and ensure a smooth transition for new members is crucial.

Diverse Recruitment and Outreach: Different recruitment and outreach strategies have led to varied representations and effectiveness in the advisory bodies. Ensuring that these strategies are well-suited to local contexts and can effectively engage a diverse cross-section of society is important. The experience of Bialystok, which recruited the largest number of advisory boards, shows that the wider the range of different stakeholders involved, the greater the chances of generating interdisciplinary ideas. In the case of MUB, the councils included people who were involved in the day-to-day decision-making of the city's social and health policies. There were also representatives of NGOs, the education sector and entrepreneurs. As they themselves pointed out, this is the only such group in the city that brings together different realities and approaches to problem solving, which is of paramount value. We therefore suggest that the composition of future councils should be as diverse as possible, but that it should be made up of socially committed people.

Resource Allocation: In Greifswald and Rotterdam, the uncertainty surrounding the future of these bodies due to staff and funding limitations poses a significant challenge. Ensuring adequate resources and support is vital for the maintenance and effectiveness of the advisory groups.

Actionability of Discussions: Translating discussions within advisory bodies into concrete actions is essential for increasing involvement and motivation. Developing effective mechanisms for this translation is a challenge that needs to be addressed to enhance the impact of the advisory bodies.

4. Recommendations for Future Projects

Prioritize Inclusive Governance: Future projects should emphasize the establishment of diverse and inclusive advisory bodies from the outset, ensuring varied perspectives in decision-making. The evaluation of the advisory bodies identified the need for a clear translation of discussions into concrete actions to increase the involvement and motivation of their members. The form of such actionability remains to be developed, e.g. official positions, memoranda, letters of support, press conferences, reports and studies. It was also noted that a regulated internal structure of the body, i.e. a (periodical) executive committee with periodic

representational powers, could be conducive to this. It is important that the positions always reflect democratic discussions within the advisory bodies.

Commit to Continuous Evaluation: Implement a framework for regular assessment and refinement of governance structures to adapt to changing needs and challenges. We recommend that the basis of such advisory bodies should be regular internal evaluation and audit, both at the level of individual members and at the level of the group as a whole. This will allow better adjustment of the group's work and development directions.

Foster Open Communication and Collaboration: Encourage a culture of open dialogue and joint efforts among all stakeholders to enhance project effectiveness and stakeholder satisfaction. In our view, advisory bodies should evolve towards greater autonomy, so that they can communicate externally independently, but in collaboration with scientific projects. They should also have more opportunities for inclusive collaboration with external actors.

Adapt and Innovate Based on Experience: Utilize the insights and experiences from past projects to inform and innovate governance strategies, ensuring they are responsive and effective. We strongly recommend that future similar advisory bodies choose to report regularly on their experiences as an organisation in written studies. Functional aspects, lessons learned and observations are also important in this regard.

5. Conclusion.

The JoinUs4Health project's WP4 has made considerable progress in fostering inclusive governance and collaboration through the establishment of Advisory Bodies in three countries. These bodies have successfully involved a diverse group of stakeholders, enhancing the project's approach through regular meetings and the exchange of experiences, particularly noted in Bialystok. However, challenges such as sustainability, member turnover, and the need for diverse recruitment strategies have been identified, alongside the imperative for actionable outcomes from discussions. The evaluation of advisory activities has highlighted the importance of continuous improvement and the need to increase the potential effectiveness of such bodies. The experiences from different cohorts, especially the broad representation and interdisciplinary approach in Bialystok, provide valuable insights for future governance models. However, concerns about resource allocation and the future of these advisory bodies in Greifswald and Rotterdam indicate the necessity for a sustainable support system. In light of these observations, several recommendations have been proposed for future projects. Emphasizing the establishment of diverse and inclusive advisory bodies from the outset is crucial for ensuring varied perspectives and democratic decision-making. Regular internal evaluations and audits are recommended to refine the governance structures and adapt to changing needs. Furthermore, fostering a culture of open communication and collaboration,

and providing advisory bodies with more autonomy and external collaboration opportunities, are seen as vital steps toward enhancing project effectiveness and stakeholder satisfaction. In conclusion, while the WP4 achievements of the JoinUs4Health project lay a solid foundation for effective governance and stakeholder engagement, it's clear that continuous effort, innovation, and adaptation based on experience are necessary. Future projects should build on these lessons, prioritizing inclusive governance, continuous evaluation, open collaboration, and resource sustainability to ensure the long-term success and impact of advisory bodies in research governance. This approach will not only improve the effectiveness of such bodies but also ensure their relevance and responsiveness to the evolving landscape of scientific research and community engagement.

Public Engagement and Platform Development and Bi-Directional Co-Working and Platform Usage

1. Achievements

Promising Developments: The online platform has shown considerable potential in promoting co-creation and multilateral communication, thus laying the foundation for active public engagement. The platform could play a crucial role in facilitating high quality citizen science projects, enabling users to contribute meaningfully to research (currently a ready-to-use toolkit for use in other projects).

User-Centric Design and Engagement: The platform's emphasis on user initiative, collaboration, and co-creation is commendable, providing a conducive environment for citizen science and public participation. Leaving the possibility of generating activity and traffic to the platform on the side of the user, who can be a representative of any stakeholder group, is crucial from the perspective of a bottom-up approach. However, it should be remembered that scientists are also such a group, so producing and publishing content that stimulates local action does not contradict the fundamentals of RRI.

2. Impact of Proposed Institutional Changes

Promotion of Public Engagement: By providing a space for dialogue and contribution, the platform has the potential to significantly promote public engagement in the research process. In Bialystok in particular, the platform was promoted through numerous offline events supported by online information campaigns. This is reflected in the statistics of visits to the platform. This seems to be an excellent starting point for realising the potential of this tool in the future. Ready-made solutions, supported by appropriate facilitation (necessarily with staff delegated for this purpose), can gain popularity and become a tool in the hands of local

community decision-makers (e.g. participatory budgeting issues, voting on scientific and health issues).

3. Challenges and Considerations and Recommendations for Future Projects

Verification of Engagement: While the platform is believed to have high public engagement potential, more time and data are needed to verify this hypothesis comprehensively. Unfortunately, significant delays due to a lack of project vision, legal challenges and data security have meant that the full functionality of the platform has not been fully tested by real users. The proposed solution is to use the platform in the educational process at secondary school and university level. An important element is the continuous evaluation of solutions and ensuring further technological development. It also seems that each language version of the platform should be maintained on a national server, which implies legal requirements and further possibilities to use external applications to support group processes on the platform. Explaining such legal complexities from the perspective of a country-specific legal system is easier than combining international applications.

Sustaining Interest and Participation and Foster Community and Collaboration: Ensuring sustained user interest and participation over time is a challenge that needs ongoing attention. The online campaigns were a very important channel for promoting the platform, reinforcing the message of the offline activities that make up the information events. This mix of project promotion and communication seems to have been the most effective solution. On the other hand, in the initial phase of crowdsourcing platforms, it is necessary to stimulate the activity of their users by creating content, initiating discussions and motivating action. Only when a group of regularly active users of the platform has been built up can it be assumed that they will generate content themselves and attract other interested parties.

Facilitation Staff Engagement: JoinUs4Health has planned a large number of tasks, reflected in a large number of milestones and deliverables. At the same time, it was not possible to employ more people due to budget constraints. In the case of MUB, internal regulations did not allow the full pool to be used for salaries. In addition, it was unclear for a long time whether it was possible to increase the number of staff planned for a particular WP. All in all, this limited the possibilities to devote time to additional issues, e.g. creating content for the online platform, interaction activities, facilitation.

Promote Awareness and Accessibility: Increase efforts to promote the platform and its projects, ensuring that it reaches a wider audience and remains accessible to all potential users. There are still large reserves to be developed in terms of presenting the possibilities of the platform to external stakeholders such as NGOs, public authorities and businesses. The project has not

developed an offer that simulates the path of use of our tool by different groups. It seems that this would be an added value with potential for interest in the platform.

4. Conclusion.

The JoinUs4Health project's online platform has laid a promising foundation for improving public engagement with scientific research. While the ultimate capacity of the platform to engage the public is still being evaluated, its initial success in fostering co-creation, collaboration and multilateral communication is noteworthy. To capitalise on this early promise, future initiatives should not only focus on continuous platform improvement and community building, but also address the challenges identified, such as verifying engagement potential, sustaining user interest, and ensuring robust facilitation and staff engagement. In particular, strategies should include promoting awareness and accessibility of the platform to reach a wider audience, including NGOs, government and business. Efforts to simulate the journey of tool use by different groups and develop offerings tailored to their needs could significantly increase the relevance and usefulness of the platform. In addition, addressing the legal and technical complexities of maintaining national server versions of the platform can further personalise and secure the user experience. In addition, a mix of project promotion methods, including online campaigns and offline activities, should be used to reinforce the message and value of the platform. By creating content, initiating discussion and motivating action, projects can stimulate user activity and build a community of regularly active users who in turn generate content and attract others. Robust evaluation mechanisms are essential to assess the impact of these strategies and guide future adaptations. By learning from the experiences and challenges of the JoinUs4Health project, similar initiatives can aim to achieve greater impact by fostering a more informed, engaged and collaborative public. With a commitment to these multi-faceted strategies, the potential of online platforms to promote citizen science and public engagement in research can be fully realised.

Science Literacy and University Engagement

1. Achievements

Overview:

RRI Strategy Integration: The project has successfully integrated RRI strategies and principles into university policies and practices, setting a standard for future scientific endeavors.

Collaborative Engagements: By fostering collaboration between scientists and community representatives, the project has bridged the gap between research and public understanding.

Comprehensive Educational Approaches: The implementation of both online and offline lessons has broadened the reach and accessibility of scientific education, actively involving students and community members.

Detailed examples from each centre:

Rotterdam

- "From Science to Society" Course: This Bachelor-level course provided a comprehensive introduction to open science, science communication, and public engagement. The curriculum was designed to encourage critical thinking and practical application through group projects, with content reflecting on the JoinUs4Health platform.
- Junior Medical School & Recognition Systems: High school students were involved in scientific research during summer breaks, with their projects contributing to broader societal discussions. The program aimed to foster early interest and engagement in RRI principles. Additionally, the rethinking of academic recognition systems at Erasmus University Rotterdam signifies an institutional shift towards valuing societal impact and RRI principles.

Greifswald

- Facultative Courses: Two courses offered students the opportunity to dive deep into RRI principles or explore the JoinUs4Health concept through case studies. These courses aimed to provide a hands-on understanding of RRI's role and application in scientific research.

Bialystok

- Hackathon for Health & Research Café: These events engaged local secondary students and the broader community in understanding and applying RRI principles. The Hackathon for Health allowed students to create socially impactful campaigns based on real research data, while the Research Café facilitated discussions on the therapeutic effects of nature, engaging professional scientists and practitioners.
- School Initiatives & Podcasts: Model lessons and workshops introduced RRI to secondary school students, while a youth podcast team created episodes discussing RRI, cohort studies, and related challenges. These initiatives aimed to build science literacy and RRI understanding from an early age.
- Informational Materials & Citizen Science Week: The production of booklets and films on health issues and cohort study participation aimed to raise public awareness and

understanding. The Citizen Science Week, complemented by various events, further promoted public engagement in scientific research.

2. Impact of Proposed Institutional Changes

Foundation for Understanding: These initiatives have laid the groundwork for deeper engagement and understanding of scientific research within local communities. As the project developed over the following months, we experienced an interesting phenomenon. Initially, the academic community around cohort studies looked at JoinUs4Health with some distance, doubting the success of the project, or at least not understanding its main objective. As we approached the end of the project, more and more academics in discussions emphasized the importance of sharing knowledge with the local community, and this was reflected in the inclusion of such theses in several presentations at the Towards Comprehensive Population Studies II conference and the accompanying discussions. This leads us to conclude that in our communities, at least among collaborating researchers, there has been an increased openness to the strategies promoted in RRI.

Strengthened Partnerships: Ongoing collaboration between educational institutions, researchers, and the community has strengthened the network of support for science literacy. During the aforementioned conference, cohort study representatives from Germany, the Netherlands, Spain, Greece and Poland unanimously expressed their willingness to apply for funding for similar initiatives such as Joinus4Health, seeing this as a great hope for an even greater societal impact of population-based research.

3. Challenges and Considerations/Recommendations for future projects.

Long-term Visibility of Change: Recognizing that changes in science literacy are more visible over a prolonged period, the project acknowledges the need for continued efforts and long-term assessment. Measuring the real impact on scientific literacy in the local community, on the general perception of science, is a very difficult task in the short term. These are social changes observed over many years and reflected in macro indicators - demographic, economic, social, cultural, etc.

Integration and Adaptation: Ongoing integration of RRI principles and adapting to evolving educational needs and methodologies remain key challenges. Although curricula for courses, studies or lessons for secondary schools on RRI issues have been prepared, a further step seems necessary at the level of decision-makers in the education sector to ensure that these elements are reflected in regional or national education standards. From the perspective of the social innovation prototype project, this level proved difficult to access.

4. Conclusion.

The JoinUs4Health project has taken important steps towards enhancing science literacy and integrating RRI principles into educational and community practices. While the immediate impact is evident, the true measure of success will be observed over a longer term. By maintaining a commitment to these initiatives, continuously evaluating their effectiveness, and adapting to emerging needs and challenges, the project can significantly contribute to a more informed and engaged society, ready to participate actively in scientific discourse and decision-making.

RRI and Rewarding System Integration

1. Achievements

Upgraded Focus on RRI: The project shifted from informal to formal support for RRI, establishing dedicated research lines and leadership roles, such as the 'Responsible Research' initiative at the Department of Epidemiology, Erasmus MC. This signifies a deeper institutional commitment to RRI principles.

Institutional Pilot Programs: Innovative pilot programs, like those at Erasmus MC, were implemented to reward departments based on qualitative and inclusive success indicators. This represents a significant step toward recognizing and rewarding RRI activities within academic institutions.

Operationalization and Promotion of RRI: Key positions and strategies were developed to operationalize RRI across various levels of research, education, and outreach, ensuring the principles are embedded in daily activities and broader departmental strategies.

It should be noted that the greatest progress in this institutional change has been made in the Netherlands. Unfortunately, in both Poland and Germany, the traditionally structured higher education system does not facilitate discussions on the evaluation of science based on non-parametric indicators.

2. Impact of Proposed Institutional Changes

Promotion of Public Engagement and RRI: The changes have the potential to significantly promote public engagement and the integration of RRI in the research process. Educational activities and the promotion of RRI principles could lead to a more informed and involved academic community. Incorporating RRI activities into the rules for rewarding scientists is a multi-step process that needs to be linked together. A larger scale of public participation in the

co-creation of science is needed to attempt to assess and perhaps even parameterize it. This is necessary to establish objective metrics for rewarding scientists.

Cultural Shift in Academic Recognition: Initiatives like the narrative format for departmental rewards at Erasmus MC and the national shift in the Netherlands towards recognizing engagement indicate a progressive cultural change. These changes impact how academic success is measured and valued, encouraging a more inclusive and responsible approach to research.

3. Challenges, Considerations, and Recommendations for Future Projects

Challenges in Implementing RRI Rewards: The academic community's traditional evaluation systems pose a significant challenge. Overcoming these requires a cultural shift toward recognizing diverse forms of academic contributions and engagements. It is necessary to emphasize the social responsibility of science as an indicator on an equal footing with the typical, well-known measures of scientific performance (publications, citations, etc.).

Need for Intensive Promotion and Education: There's a crucial need to intensively promote and educate about the benefits of RRI. Understanding and support for RRI among scientists and university authorities are essential for its successful integration.

Showcasing Practical Examples: Demonstrating successful RRI projects is vital to gaining broader acceptance and understanding of RRI principles. Practical examples help illustrate the tangible benefits and potential of RRI.

Developing Evaluation and Reward Mechanisms: Future projects should focus on identifying and developing robust evaluation and reward mechanisms that align with RRI principles, ensuring they are inclusive, collaborative, and reflective of diverse contributions.

Ongoing Discussions and Adaptation: Continual dialogue with university authorities and stakeholders is crucial. Involving them in the creation or integration of RRI-related criteria into academic rewards systems ensures that changes are well-informed and widely supported.

4. Conclusion.

In conclusion, while significant strides have been made in integrating RRI and Citizen Science initiatives within academic recognition systems, ongoing efforts are required to ensure their sustainability and impact. Future projects should build upon these foundations, focusing on continuous improvement, community building, robust evaluation, and a holistic approach to fostering a more responsive, responsible, and inclusive research environment.

Mutual Learning and RRI Support

1. Achievements:

Enhanced Communication Platform: The project successfully integrated a question-answer functionality into the online platform. This development has streamlined issue categorization and improved the focus of discussions, thereby facilitating more effective stakeholder engagement.

Educational Initiatives: Notable progress has been made in the development of educational content, highlighted in particular by the comprehensive "From Science to Society" course, classroom scenarios for high school students and a series of podcasts. This course covered key areas such as open science and citizen science, and used a variety of teaching methods to promote a deep understanding of RRI principles among students from different disciplines, as well as the main challenges of research participation in cohort studies.

2. Impact of Proposed Changes

Strengthened Stakeholder Dialogue: The implementation of a structured communication platform has the potential to significantly enhance stakeholder dialogue, ensuring that various voices might be heard and considered in the research process. An environment (platform) was created to bring together all science enthusiasts, theoretical and applied perspectives, professional and non-professional, in an inclusive way. Importantly, the platform was created with the practical advice of marketing specialists who designed the colour scheme and functionalities to be user-friendly.

Promotion of RRI Principles: The educational initiatives have laid a solid foundation for promoting RRI principles. The successful application of these principles in real-world scenarios through project-based learning has demonstrated their relevance and potential impact. A good example was the path from the Health Hackathon and the work of youth teams on the health issues identified in Bialystok PLUS to the design of a social campaign, the recording of promotional videos and their publication and promotion on the Internet. Another was the recording of a series of podcasts or the development of recommendations for youth mental health prevention by the City Youth Council. To ensure greater reach and sustainability of such solutions, it is necessary to run repeat events and expand networks of influence.

3. Challenges, Considerations, and Recommendations for Future Projects

Platform Engagement and Traffic: While the communication platform is promising, its true effectiveness needs to be further validated under conditions of increased user traffic and engagement, which have been low to date.

Awareness and Integration of RRI: The current lack of widespread recognition and understanding of RRI within participating institutions highlights the need for intensified awareness-raising efforts and the integration of RRI into academic culture. It should be noted that when planning this activity, it is necessary to take into account the general cultural and systemic conditions of science, but also of society in terms of general scientific literacy, health literacy, etc.

Sustaining Engagement: Maintaining continuous user interest and participation in RRI activities is crucial. Projects should focus on innovative strategies to keep stakeholders actively involved. As mentioned above, it is worth considering presenting the opportunities and benefits of using the platform to other stakeholders, e.g. local decision-makers (user case).

Evaluate and Adapt Communication Strategies: Continuously monitor and assess the question-answer platform's impact on engagement. Adapt strategies based on feedback to improve its effectiveness. In this case, it is absolutely necessary to employ staff to facilitate traffic on the platform.

4. Conclusion.

The JoinUs4Health project has contributed to the field of mutual learning and Responsible Research and Innovation (RRI) by implementing a communication platform and educational initiatives. These developments have aimed to enhance stakeholder engagement and facilitate an understanding of RRI principles. However, the project faces challenges in increasing platform engagement, broadening RRI recognition, and maintaining ongoing participation. Future directions may include refining communication strategies, enhancing platform functionality, and fostering a more integrated approach to RRI within academic and public domains. Addressing these challenges and opportunities is vital for the continued development and impact of RRI-focused initiatives.

Communication and Dissemination: Knowledge Translation

1. Achievements

Enhanced Accessibility: Notable advancements have been made to make scientific content more accessible and engaging, aligning with the overarching goal of knowledge translation. Examples include information brochures on cohort studies written in a simple and understandable way, as well as lesson plans and podcasts on cohort studies.

Platform Adaptability: The online platform has been continuously adapted and improved based on user feedback, refining the approach to knowledge translation and enhancing user

experience. The Citizen Science Boards and the Monitoring and Evaluation Group have made very important contributions to the development of the platform, and we are particularly grateful to them.

Development of Knowledge Translation Principles: Plans are underway to develop and publish the main principles of knowledge translation for scientists in Bialystok, an initiative aimed at broadening the reach and impact of knowledge translation efforts. A new internal project is already underway at the MUB to encourage researchers to write simplified descriptions of their own articles, which are then published on the university's social media. The aim is to bring scientific discoveries closer to the local community. The Bialystok PLUS research centre regularly welcomes youth groups to learn about the work of scientists and scientific research methodology. These initiatives are based on the observations and discussions carried out as part of JoinUs4Health. It is also worth noting that in Rotterdam, the What the Health podcast series was another great example of such an approach.

2. Impact of Proposed Changes

Strengthened Stakeholder Dialogue: The introduction of a structured communication platform has the potential to significantly enhance stakeholder dialogue, creating an inclusive environment where diverse perspectives are heard and considered.

Promotion of RRI Principles: Educational initiatives have laid a solid foundation for promoting RRI principles, with the successful application of these principles in real-world scenarios through project-based learning demonstrating their relevance and potential impact (see Hackathon for health example).

3. Challenges, Considerations, and Recommendations for Future Projects

Platform Engagement and Traffic: As noted above, the true effectiveness of the communication platform in promoting engagement and facilitating meaningful dialogue needs to be further validated, particularly under conditions of increased user traffic.

Awareness and Integration of RRI: There is a need for intensified efforts to raise awareness and integrate RRI into academic and public domains. When planning these activities, it is necessary to consider the cultural and systemic conditions of science and society.

Sustaining Engagement: Maintaining ongoing user interest and participation in RRI activities is crucial. Projects should consider innovative strategies to keep stakeholders actively involved. In particular, we strongly recommend offline events to increase online traffic on the platform.

Evaluation of Effectiveness: The evaluation of the JoinUs4Health project's aided awareness among Bialystok residents showed 17% familiarity with the brand. This indicates a relatively high level of brand recognition for a young brand. However, the results may be slightly inflated due to the specifics of the surveyed sample. Further, the platform concept test results indicate a need for improved brand awareness, targeted segmentation, and possibly addressing the innovativeness or perceived relevance of the service (see Deliverable 6.7).

4. Conclusion.

The JoinUs4Health project has made considerable progress in enhancing knowledge translation and supporting RRI. The development of an enhanced communication platform and various educational initiatives are significant steps towards fostering a more inclusive and collaborative research environment. However, challenges in engagement, awareness, and sustained participation highlight areas for future focus. The project's commitment to developing knowledge translation principles in Bialystok and the unexpected level of brand recognition in the area are promising developments. Continuous improvement, broader promotion of RRI, and a focus on specific target segments, such as students and NGO representatives, will be crucial for advancing the understanding and application of scientific knowledge. By addressing these areas, the project can contribute significantly to a more informed and engaged community and shape a future where knowledge translation and RRI are integral to public engagement in science.

Final summary

Our comprehensive evaluation of the JoinUs4Health consortium's efforts highlights our innovative approach to integrating responsible research and innovation (RRI) with population-based cohort studies. We have focused on developing and disseminating strategic recommendations and observations critical to navigating the complexities of implementing RRI within a diverse institutional framework. We recognise the inherent difficulties in orchestrating multi-faceted institutional change. Our pioneering approach required bringing together diverse methodologies and cultural perspectives from different research centres, each with its own set of practices and norms. This amalgamation posed significant coordination challenges, particularly in aligning the different work streams within the different work packages. We highlight the critical need for robust coordination mechanisms to effectively manage this complexity and ensure a coherent approach to project implementation. We also highlight the intricate interrelationships between different tasks and work packages. These interdependencies added layers of complexity to project delivery and required a high degree of synchronisation and communication between the different teams involved. Managing these linkages was identified as a significant challenge, highlighting the need for improved collaboration strategies and tools to facilitate seamless integration across the many components of the project. It also highlights the time-sensitive nature of observing the end results of sustainable institutional change. Achieving lasting and meaningful change is a long-term endeavour that unfolds over time and beyond the confines of project timelines. We argue for longer project durations and ongoing support mechanisms to allow these changes to fully mature and manifest within the institutions involved.

In essence, our findings and recommendations highlight the innovative yet challenging nature of implementing RRI in conjunction with population-based cohort studies. The insights we have gained provide a deep understanding of the complexity of multi-faceted institutional change, the critical role of coordination and collaboration, and the patience required to witness the sustainable fruits of these efforts. As such, our report serves as an important resource, providing guidance and direction for future projects seeking to embark on similar journeys to promote inclusive, responsive and responsible research environments.

We are very proud of the impact and efforts made by all the consortium partners over the three years of the JoinUs4Health project. The collaboration, commitment and hard work of each partner has been fundamental to our achievements and the significant progress we have made. The journey, full of challenges and successes, has provided us with important lessons

that are invaluable for our continued growth and contribution to the field. We would like to express our sincere gratitude to all our partners for their significant contributions, for the exchange of intellectual value and for bringing a heightened sensitivity to the social role of science within the often rigid world of hard scientific methodology. The different perspectives and expertise that each partner brought to the table have enriched the project and fostered a multifaceted approach to the complex issues we set out to address.

As well as moving the project forward, the collaboration has created a network of shared knowledge and experience that will influence our work and the wider scientific community for years to come. The lessons learned during this time are now embedded in our collective understanding and will guide us as we move forward with new initiatives and endeavours.

Once again, we would like to express our sincere gratitude to all the consortium partners for their tremendous contributions. Together, we have made significant progress in advancing responsible research and innovation and enhancing the societal responsiveness of science. We look forward to applying these achievements and lessons learned to our future projects and collaborations.

Work Package Institutional Changes Team