Join Us to Optimize Health Through Cohort Research

Deliverable 4.2: Report on the implementation of institutional changes

Version 1.0

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Executive summary

This implementation report expands on the foundation established in the 'Deliverable 4.1' document, which outlined the conceptualized institutional changes within the JoinUs4Health consortium. The consortium's primary objective is to permanently implement at least six institutional changes in participating cohort study institutions, with each center implementing activities tailored to their local context and needs.

The planned institutional changes cover six areas: Responsible Research and Innovation (RRI) Implementation, Science Literacy, Public Engagement, Open Access, Governance, and Communication & Dissemination. Based on cohort study leaders' responses, a selection of changes was compiled for implementation. This report provides an in-depth overview of the tasks to be undertaken during the implementation phase, considering their positioning within the remaining project period and beyond.

Achieving institutional change is a complex, multi-stage process, and the final form of these changes may deviate from initial plans due to various factors. The project team is dedicated to monitoring and evaluating the assumed institutional changes beyond the project's completion to ensure sustainability. While consortium partners may implement institutional changes differently based on individual preferences, needs, and feasibility, MUB, as Work Package 4 (WP 4) leader, will promote a unified approach for future comparative analysis.

The report is structured according to Deliverable 4.1, presenting the planned institutional changes and corresponding tasks. Each change's implementation is described with an introduction, commentary, summary of accomplishments, discussion of next steps, and conclusions. This structure aims to make the complex process of institutional change implementation more accessible.

It should be noted, however, that the phase in which the Joinus4Health project is in contains some delays, the background of which has been explained on several occasions. A common denominator is the will to integrate approaches between culturally divergent centres conducting cohort studies. This means that many of the institutional changes have not achieved their full form and, consequently, at the time of writing the report, it is not possible to evaluate them. It would seem that from the perspective of the project's objectives, and in particular, the implementation and sustainability of the institutional changes, it would be advisable to extend the project by at least the estimated time between the start of the project and the launch of its key activities (primarily the online platform).

From conceptualization to implementation - the challenging path of multiple interdependencies of institutional change

This implementation report builds upon the groundwork laid out in the 'Deliverable 4.1' document, which outlines the institutional changes conceptualized and selected for implementation within the JoinUs4Health consortium. With feedback from study representatives in UMG, EMC, and MUB, the primary objective of the consortium is to permanently implement a minimum of six institutional changes in the participating cohort study institutions. It is important to note that each cohort center will implement slightly different activities within the JoinUs4Health project, depending on their local context and needs.

The institutional changes planned at the conceptualization stage covered six areas: RRI Implementation, Science Literacy, Public Engagement, Open Access, Governance, and Communication & Dissemination. Within these areas, specific sub-areas and activities were identified. Based on the importance and feasibility of the institutional changes, cohort study leaders provided their responses to compile a selection of changes for implementation.

In this report, we provide a comprehensive overview of the tasks to be undertaken during the implementation phase of the selected institutional changes, while considering their positioning within the remaining project period and beyond. We acknowledge that achieving institutional change is a process that may involve multiple stages, and the final form of these changes may deviate from the initial plans due to various factors, such as internal regulations or the ongoing SARS-CoV-2 pandemic.

The institutional changes planned in the project are multi-level in nature and will largely be achieved through the implementation of tasks across multiple work packages. As the project progresses, the final form of these changes will depend on the capacities and decisions made within the participating institutions. While the achievement of sustainable institutional change may not be fully demonstrated during the project's duration, the project team is committed to ensuring that monitoring and evaluation of the assumed institutional changes will continue in the years following the project's completion.

It is crucial to emphasize that institutional changes can be implemented differently by consortium partners, depending on individual preferences, needs, and feasibility assessments. However, as the WP 4 leader, MUB will encourage a unified approach to enable comparative analysis of the implemented changes in the future.

This report has been structured in line with Deliverable 4.1, i.e. it reflects the institutional changes planned and the tasks assigned to each of them, which should bring them closer to final, sustainable implementation. The description of the implementation of each change has been prepared in a standard way, i.e. first a brief introduction of what each part of the report is about, including the tasks carried out, then a commentary on each of them, and finally a summary of what has been successfully implemented, a discussion of the next steps and conclusions. Hopefully, this arrangement will make contents more accessible for the reader.

Open Access Policy and Public Data Dictionaries

Introduction

This part of the report outlines the progress and outcomes of the implementation of the Open Access Policy and the creation of user-friendly public data dictionaries within the institutions conducting cohort studies. Data dictionaries are essential tools for organizing and explaining information about a dataset. They are used to clearly describe the data's structure, content, and relationships, making it easier to understand and use. In science, data dictionaries help standardize data collection, improve data quality, support collaboration, and promote transparency in research. They are valuable for both researchers and non-professional users, as they ensure the data is accurate, consistent, and easier to understand.

In line with the project timeline, the WP 4 team has foreseen the following specific tasks:

T1. Analysis of the data dictionaries in each study in terms of their accessibility, readability, and openness

T2. A comparative overview indicating differences between cohort studies

T3. Propose changes to enhance the user-friendly paradigm

Analysis of Data Dictionaries (T1)

The WP4 team has reviewed the data dictionaries from each participating cohort institution. The analysis focused on three main criteria: accessibility, readability, and openness.

- Study of Health in Pomerania (SHIP): Data dictionaries are accessible at https://www.fvcm.med.uni-greifswald.de/dd_service/data_use_intro.php
- Rotterdam Study: Data dictionaries are not publicly accessible
- Bialystok PLUS: Currently accessible upon request. However, work is underway on a new website where the dataset will be implemented and made more readily available.

The results show a range of practices with some institutions having easily accessible and well-documented data dictionaries, while others have more restricted access and limited documentation. This item included discussions on the feasibility and readiness of making changes, their desirability and even unifying the presentation of data across cohorts. We originally had highlighted differences between the cohorts, consisting of the stage of advancement of the research projects themselves and the consolidation of the presence of the 'cohort brands' in the consciousness of the local communities. Our discussions highlighted also differences in the established rules for making the data public.

Cohort studies that have operated in the European research space for many years have a fixed pathway to data access, based primarily on a system of requesting access with a description of the potential research project taking into account the data of the cohort centre, and subsequent approval by the cohort steering committee. It should be added that, apart from Bialystok PLUS, both the Study of Health in Pomerania and the Rotterdam Study are well recognised in Europe, making the need for changes in the way data are presented and made available perhaps less important. In Bialystok, on the other hand, the study needs to be widely promoted so that it can serve a wider range of stakeholders. Hence, the willingness to make the data dictionaries publicly available, which is intended to transparently mediate the promotion of the study and increase the circle of its scientific beneficiaries.

Plan: It was agreed that in the future it would be valuable to aim for mutual coordination in the management of the way data are collected and in harmonising the dictionaries with a view to seeing the potential for inter-cohort comparative analysis. However, this requires a huge amount of work that was not foreseen in the JoinUs4Health project. We accept, however, that simply stimulating discussion, raising open questions and agreeing on the potential for future coordination activities is a rewarding element of institutional change.

Comparative Overview (T2)

The comparative overview identified several key differences between the data dictionaries of the participating cohort studies. Some of these differences include:

a) Variation in the format of data dictionaries (e.g., Excel, or online platforms)
b) Inconsistency in the level of detail provided for each variable (e.g., descriptions, units, and coding schemes)
c) Disparity in the use of standard terminologies and ontologies
d) Variation in access restrictions

Proposed Changes (T3)

Based on the analysis and comparative overview, the WP4 team has proposed the following changes to enhance the user-friendly paradigm:

- Standardize the format of data dictionaries across all cohort studies, preferably using a machine-readable format (e.g. XML)
- Ensure comprehensive documentation of each variable, including detailed descriptions, units, and coding schemes
- Adopt a common set of terminologies and ontologies to facilitate data integration and interoperability

- Promote open access to data dictionaries by minimizing access restrictions

It should be clearly emphasised that the points indicated above are only recommendations based on our analyses, internal discussions within the WP4 team and the cohort partners. This means that their final implementation in each case depends on the decision and will of the centres conducting the cohort study and are open for further discussion.

Implementation and Progress

Since the beginning of the implementation phase, the WP4 team has been working closely with the participating institutions to address the proposed changes. The following have been achieved:

- Data dictionaries have been developed in Bialystok PLUS and will be implemented online once the new visual identity of the cohort and the website are ready
- A pipeline for the presentation of data from cohort studies is ready (in the implementation phase on the JoinUs4Health platform - in the first phase it will be based on Bialystok PLUS with the possibility of adding other cohorts). This pipeline will typically target users who represent a variety of stakeholders (not necessarily professional researchers) and may reinforce the desire to take initiatives or provide a valuable source of regionally relevant health information.
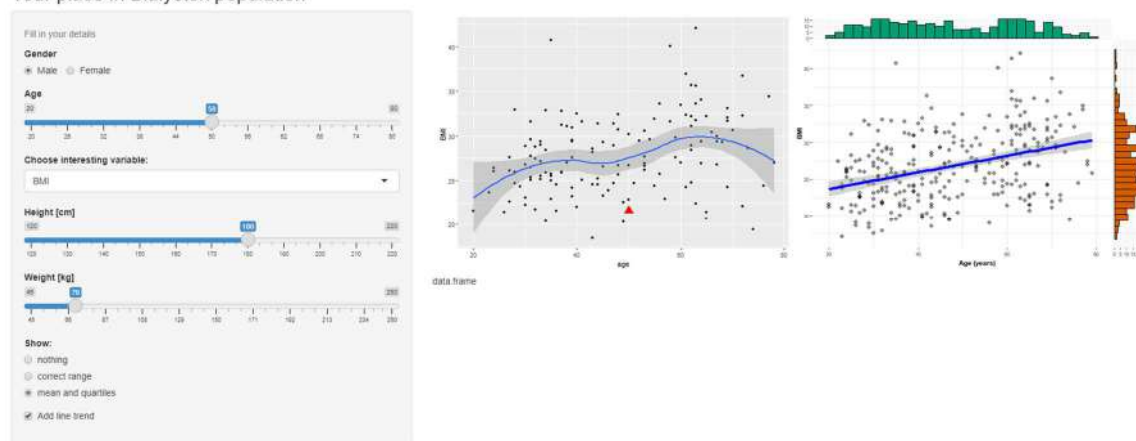

Figure 1. Screenshot of draft version of pipeline

Next Steps

The WP4 team will continue to monitor the implementation process and provide support to participating institutions as needed. The next steps in the process include:

- exchange of experience on the possibilities of developing forms of data presentation (including dictionaries) as a step towards semi-open data access

Conclusion

The implementation of the Open Access Policy and the creation of user-friendly public data dictionaries within the cohort studies engaged in JoinUs4Health have resulted in a constructive analysis and comparison of existing data dictionaries, leading to valuable recommendations for improvement. The WP4 team's proposed changes aim to standardize formats, enhance documentation, adopt common terminologies, and promote open access to data dictionaries. Although the implementation of these recommendations ultimately depends on the decision of each participating institution, progress has been made in areas such as developing data dictionaries for Bialystok PLUS and creating a pipeline for data presentation on the JoinUs4Health platform (not-published yet). As the project moves forward, the WP4 team will continue to support participating institutions, monitor the implementation process, and explore new opportunities for developing data presentation forms. This collaborative effort has the potential to significantly improve data accessibility, readability, and openness, ultimately benefiting a wide range of stakeholders and fostering valuable, regionally relevant health information. Our hope is that this especially promotes access to combined results across two or three of the participating cohort partners.

Conditional Approval and Data Access

Introduction

This section of the report outlines the progress and outcomes of implementing conditional approval and data access policies within the JoinUs4Health consortium. The goal of these efforts is to provide clear and understandable information for the participants of the JoinUs4Health project, while ensuring legal and ethical compliance. The following specific tasks have been foreseen:

T1. Compare applications for accessing data, making forms available in one place (website)

T2. Encourage the creation and publication of transparent data access regulations for cohort studies

T3. Develop a transparent flowchart of the data access application process

Comparison of Data Access Applications (T1)

The team has discussed and compared data access applications from each participating study within the JoinUs4Health consortium. Standardization of application forms to apply for individual-level data across cohort studies is impossible. The main reason for this is the complexity of the process of retrieving data from a cohort repository, which consists of multiple

steps each time involving activities carried out by a member of staff from the cohort unit. The above is the result of discussion, but ultimately tests should be undertaken to properly estimate the scale of data access requests. One solution to this situation is the data presentation pipeline prepared by MUB - it will eventually allow the presentation of aggregated data as well as samples showing the distributions of selected variables.

Transparent Data Access Regulations (T2)

Although this task has not yet been achieved due to its difficulty related to changing the approach to data sharing, it has been decided that there will be no possibility of standardizing the way data is obtained because the current approach is well-established. Instead, it has been decided that the platform will promote general information about the data access mechanism and refer to the specifics on the side of the entity conducting the cohorts. In the future, to promote transparency, the team will encourage participating cohort studies to create or consolidate good practice and publish clear data access regulations. This would lead to the development of standardized guidelines for data access, which would address key concerns such as data privacy, legal requirements, and ethical considerations. These guidelines or external links to such guidelines will be made available on the project website, ensuring that researchers will be aware of the conditions and requirements for data access in the future.

Transparent Flowchart for Data Access Application Process (T3)

The team has also developed a transparent flowchart that outlines the data access application process. This flowchart provides a step-by-step guide for researchers, detailing the necessary actions to request and gain access to data within the JoinUs4Health consortium. By making the flowchart available on the project website, researchers have a clear understanding of the process and can easily navigate through the various stages. As mentioned earlier, we have assumed that the concretised access path to the data (forms, rules for describing the project) are typical for the cohort, so from the platform we can redirect the interested party to contact the directly responsible persons on the cohort side
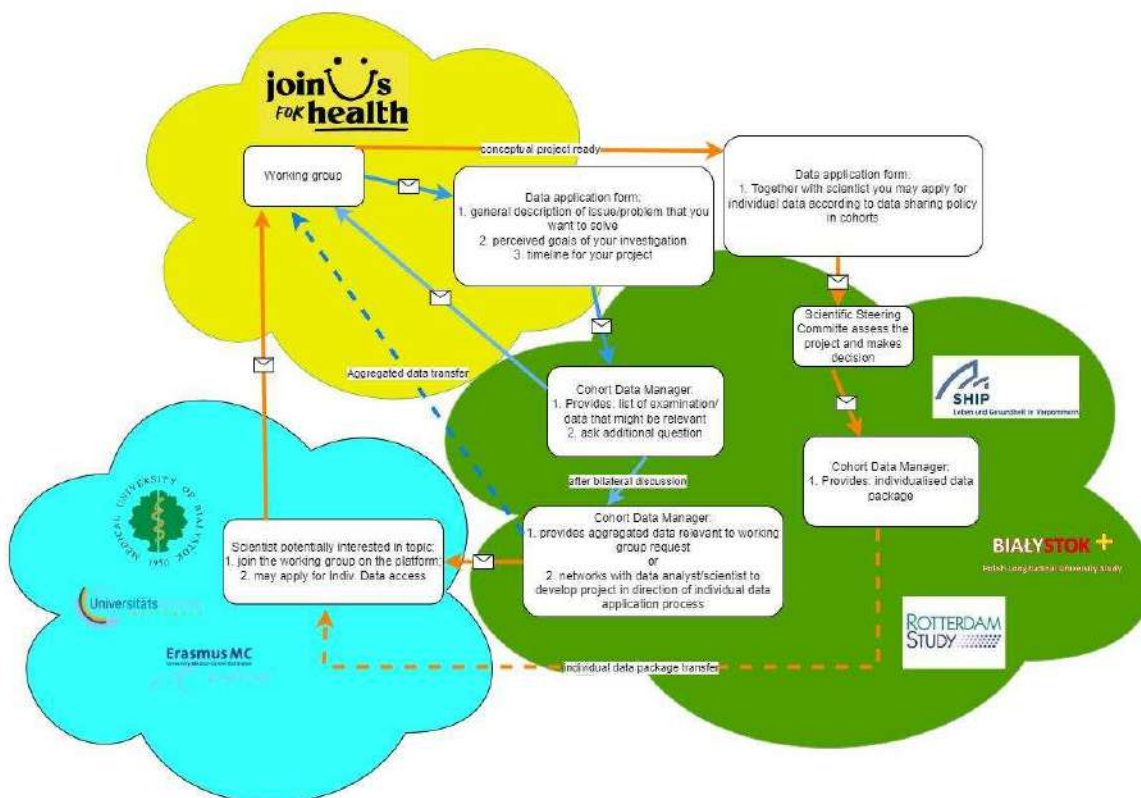
Figure 2. Flowchart showing data access options

Implementation and Progress

Reasonable progress has been made in implementing conditional approval and data access policies within the JoinUs4Health consortium. The following milestones have been achieved:

- Discussion and agreement of standardized guidelines for data access under JoinUs4Health (aggregated data as rule, individual data only on inquiry-approval-basis)
- Availability of a transparent flowchart for the data access application process (soon on the project website)

Next Steps

The team will continue to monitor the implementation of these policies and provide support as needed. The next steps in the process include:

- Promoting the adoption of the unified data access application form and guidelines across all participating cohort studies
- Continuously updating the data access regulations and flowchart to reflect any changes in legal or ethical requirements
- Assessing the effectiveness of the implemented policies and making adjustments as necessary

Conclusion

In summary, the JoinUs4Health consortium has made progress in implementing conditional approval and data access policies. The team has compared data access applications, encouraged the creation and publication of transparent data access regulations, and developed a transparent flowchart for the data access application process. Although standardization of data access application forms has proven to be challenging, the consortium has adapted by promoting general information and guidelines for data access. The next steps involve the creation and promotion of the unified data access application form, continuous updates to the regulations and flowchart, and the ongoing assessment of the effectiveness of the implemented policies. Overall, these efforts aim to streamline the data access process, ensuring that researchers have a clear understanding of the requirements and can successfully navigate the legal and ethical landscape associated with data sharing within the JoinUs4Health consortium.

Governance and Advisory Bodies

Introduction

This part of the report outlines the progress and outcomes of implementing governance changes within the project, with a focus on the creation of advisory bodies in each participating country. These bodies, the Citizen Science Board and Monitoring and Evaluation Group, aim to include all beneficiaries in the decision-making process. The following specific tasks were carried out:

T1. Development of bylaws/rules for the Citizen Science Board

T2. Development of rules of procedure/regulations for the Monitoring and Evaluation Group

T3. Organisation of the recruitment process of both bodies

T4. Coordination of meetings of advisory bodies and support of their functioning

T5. Evaluation of the activities of advisory bodies

Development of Bylaws/Rules (T1 and T2)

The project team has developed comprehensive bylaws and rules of procedure for both the Citizen Science Board and the Monitoring and Evaluation Group. These documents outline the purpose, structure, and functioning of each body, as well as the roles and responsibilities of their members. These documents can serve as a model for future similar bodies to be set up

in other universities, although naturally they may need to be amended to suit current circumstances.

Recruitment Process (T3)

Following the establishment of bylaws and rules of procedure, the project team organized the recruitment process for both advisory bodies. A call for nominations was disseminated widely to ensure a diverse pool of candidates from various sectors, including policy makers, business representatives, citizens, scientists, educators, and NGOs. After a thorough selection process, members have been appointed to each advisory body in each participating country. Unfortunately, due to other delays in the project in terms of the final form of the online platform, the promotion of the project, in Greifswald and Rotterdam, it was not possible to recruit the fully intended composition of both bodies in time. This issue was raised several times during Project Management Team meetings and it was agreed that as the project progressed and was promoted, supplementary recruitment of advisory board members would be carried out. In Bialystok, on the other hand, it was possible to recruit the full membership of both groups quite quickly, so that regular work (meetings of both groups) was possible.

Coordination and Support (T4)

The project team has coordinated the initial meetings of the advisory bodies and provided ongoing support for their functioning. This includes the facilitation of regular meetings, the provision of necessary resources and materials, and the establishment of communication channels for effective collaboration among members. It should be added that some conclusions can be drawn from the meetings held so far about the very function of such bodies. Firstly, therefore, it was originally envisaged that the meetings would take place online. After the first observations of the Bialystok team, it was decided to allow for a hybrid formula. A large proportion of the members of both bodies in Bialystok take advantage of the opportunity to meet in person at the MUB. A second observation is that adequate information communication is maintained with the advisory boards - primarily on the progress of the project, but also in preparation for meetings. This makes the meetings themselves more effective. Thirdly, it is quite important to create opportunities for direct contact between advisory boards and the managers of the universities or the cohort study, as this shows their importance to the project and heralds the potential for the future. It is also a motivating factor for members to be more active. Fourthly, more emphasis should be placed on communicating the progress of JoinUs4Health through the social channels and networks of the members of the bodies.

Evaluation of Activities (T5)

To assess the effectiveness of the advisory bodies, the project team will conduct an evaluation of their activities in the coming months. This decision is mainly because meetings of the advisory boards are currently taking place in other cohort centers. The evaluation will include a review of meeting minutes, reports, and recommendations produced by each body. Feedback from advisory body members and other stakeholders will also be collected to identify areas for improvement and to ensure that the bodies continue to fulfill their intended roles.

Implementation and Progress

Significant progress has been made in implementing governance changes within the project. The following milestones have been achieved:

- Establishment of bylaws and rules of procedure for both the Citizen Science Board and the Monitoring and Evaluation Group
- Recruitment and appointment of advisory body members in each participating country (not full)
- Coordination and support of advisory body meetings and activities

Next Steps

The project team will continue to support and monitor the functioning of the advisory bodies, with a focus on the following tasks:

- Ensuring ongoing engagement and active participation of advisory body members
- Facilitating regular communication and collaboration among consortium partners (best practices exchange)
- Continuously evaluating and refining the roles and functioning of the advisory bodies

Conclusion

The implementation of governance changes within the JoinUs4Health has made significant progress, particularly in the creation of advisory bodies in each participating country. By developing comprehensive bylaws and rules of procedure, organizing recruitment processes, and coordinating the meetings and functioning of these bodies, the project has successfully taken steps to include a diverse range of stakeholders in the decision-making process. The ongoing engagement, communication, and collaboration among consortium partners and advisory body members have proven to be valuable in enhancing the project's overall effectiveness. Although the partners from Bialystok were the biggest beneficiaries of this cooperation, thanks to the exchange of observations and experiences, the other partners from Greifswald and Rotterdam were also able to adapt similar solutions in their groups.

In the coming months, the project team will focus on evaluating the activities of the advisory bodies and ensuring their continuous improvement. Lessons learned from these evaluations will be used to refine the roles and functioning of the advisory bodies, ensuring their continued relevance and effectiveness in achieving the project's objectives. By maintaining a strong commitment to stakeholder engagement and collaboration, the JoinUs4Health project will be better positioned to address current and future challenges and maximize its impact on public health.

Public Engagement and Platform Development

Introduction

This part outlines the progress and outcomes of implementing public engagement strategies within the JoinUs4Health project, focusing on the creation of an online platform for citizen science. This platform aims to foster co-creation and multilateral communication among stakeholders, ensuring a higher quality of generated projects. The implementation process involves both technological and procedural aspects. The following specific tasks have been completed:

T1. Design requirements for technical developments

T2. Develop technical means

T3. Develop privacy and term of use legal statement

T4. Explore different approaches and implement the most useful features

The implementation of the tasks briefly characterized below is described in detail in Deliverable 3.2.

Design Requirements for Technical Developments (T1)

The project team, in collaboration with consortium members, has established design requirements for the online platform. These requirements address key features such as community- and team-level interactions and access to source materials. Additionally, the platform has been designed to accommodate different user roles to suit the needs and perspectives of various stakeholders.

Development of Technical Means (T2)

Based on the design requirements, the project team has developed the technical infrastructure for the online platform. This includes the creation of a user-friendly interface, database systems

for storing and managing project data, and tools to facilitate collaboration among platform users.

Privacy and Terms of Use Legal Statement (T3)

To ensure legal compliance and protect user privacy, the project team has developed a comprehensive privacy policy and terms of use statement for the platform. These documents outline users' rights and responsibilities, as well as the measures taken to safeguard personal information. This information is, of course, posted on the JoinUs4Health platform and translated into the languages used by the project.

Exploration and Implementation of Useful Features (T4)

The project team has explored various approaches and features to enhance the user experience on the platform. After a thorough evaluation, the most useful features have been implemented, such as advanced search functionalities, project templates, and customizable notifications. The platform is designed to remain open and adaptable, allowing for continuous improvement based on user needs and feedback.

Implementation and Progress

Significant progress has been made in implementing public engagement strategies through the development of the online platform. The following milestones have been achieved:

- Establishment of design requirements for the platform
- Development of the technical infrastructure for the platform
- Creation of privacy policy and terms of use statement
- Implementation of useful features to enhance user experience

Next Steps

The project team will continue to support and monitor the platform, focusing on the following tasks:

- Ensuring ongoing engagement and active participation of users on the platform
- Collecting feedback from users and stakeholders to refine platform features and functionalities
- Promoting the platform among target audiences to increase its reach and impact

Conclusion

The implementation of public engagement strategies through the creation of an online platform has been promising in fostering co-creation and multilateral communication among

stakeholders within the JoinUs4Health project. At this stage, we can conclude that a tool with high public engagement potential has been created, but it will take some time to verify this hypothesis. The platform provides a user-centric approach to citizen science, emphasizing the importance of user initiative, collaboration and co-creation. The platform plays a crucial role in facilitating high-quality citizen science projects and promoting public engagement in research.

Bi-Directional Co-Working and Platform Usage

Introduction

This paragraph outlines the progress and outcomes of implementing bi-directional co-working strategies, focusing on the procedural aspects of using the online platform for citizen science. The platform usage scheme has been designed to facilitate user-driven research projects and collaborative problem-solving. The following specific tasks have been completed:

T1. Develop a path for using the platform from a user perspective

T2. Identify key roles on the platform

T3. Plan the training process and operational rules for moderators, facilitators, site administrators

T4. Maintain regular communication with the users of the platform

T5. Evaluate and implement necessary improvements

Platform Usage Path Development (T1)

The project team has developed a user-centric path for using the platform, which includes steps such as asking questions, making research suggestions, voting on topics, and forming working teams to implement research projects. This structured approach encourages collaboration and ensures that research projects are driven by the interests and needs of platform users.

Identification of Key Roles (T2)

Key roles on the platform have been identified to facilitate user-driven research projects and ensure effective collaboration. These roles include platform users, moderators, facilitators, and site administrators, each with distinct responsibilities and functions within the platform ecosystem. In particular: Site administrators are the only group with access to users and can thus change a user role (e.g. from general platform user to editor). Moderators contact site administrators if the role of a platform user needs to be changed from general user to editor or

back to general user. Moderators are permanent editors allowing them to create a new topic, task or team at any time. They then assign an editor as facilitator of a given topic, task or team.

The facilitator drafts a plan / text with potential input from the moderator and responds to user requests (e.g. comments, new contributors etc.). The moderator provides background support and input on the initial plan, implementation of activities and summary of outcomes.

Training and Operational Rules (T3)

The project team is in the process of developing a training program and operational rules for moderators, facilitators, and site administrators. This ongoing task aims to ensure that these individuals will have the necessary skills and knowledge to support users, manage research projects, and maintain the platform effectively once a unified training system is established. It is very important to prepare standards and requirements for moderators, facilitators and other users of the platform. This should furthermore be properly communicated. To this end, an instructional video is being produced.

Regular Communication with Users (T4)

To foster an active and engaged user community, the project team maintains regular communication with platform users. This includes providing updates on project progress, soliciting feedback, and addressing user concerns or inquiries in a timely manner. The initial plan was to create a periodic newsletter, which evolved into publishing content in blog form. Certainly, the frequency of published content needs to be intensified, as well as a greater variety of content. It seems that one of the main challenges is to create interesting content on an online platform that would attract more users.

Evaluation and Improvement (T5)

The project team continuously evaluates the platform and its usage to identify areas for improvement. User feedback and platform performance data are collected and analyzed to inform necessary adjustments and enhancements to the platform and its features, will also be summarised in the report constituting Milestone 9, which is currently under development. Feedback is collected at every opportunity of the activities carried out, e.g. workshops for NGOs, advisory board meetings, a hackathon for health or seminars with scientists. In addition, valuable information was obtained from the first users of the platform, who tried to implement their ideas on it. This feedback is always discussed within the Project Management Team.

Implementation and Progress

Significant progress has been made in implementing bi-directional co-working strategies and refining platform usage. The following milestones have been achieved:

- Development of a user-centric path for using the platform
- Identification of key roles and responsibilities on the platform
- Creation of training programs and operational rules for key roles (not finished yet)
- Maintenance of regular communication with platform users (progress required)
- Evaluation and implementation of necessary improvements (ongoing)

Next Steps

The project team will continue to support and monitor the platform and its usage, focusing on the following tasks:

- Ensuring ongoing engagement and active participation of users in research projects
- Providing support and guidance to moderators, facilitators, and site administrators
- Continuously evaluating and refining platform features and usage processes

Conclusion

The implementation of bi-directional co-working strategies within the JoinUs4Health project has made significant progress, with a particular focus on refining the procedural aspects of the online platform for citizen science. By developing a user-centric path for using the platform, identifying key roles and responsibilities, initiating the creation of training programs and operational rules, maintaining communication with platform users, and evaluating and implementing necessary improvements, the project has laid the groundwork for fostering effective collaboration and user-driven research projects. In the coming months, the project team will concentrate on further enhancing user engagement, supporting moderators, facilitators, and site administrators, and continuously evaluating and refining the platform features and processes.

Science Literacy and University Engagement

Introduction

This report outlines the progress and outcomes of implementing science literacy initiatives within the JoinUs4Health project, with a focus on university courses and training opportunities. The aim is to promote RRI and increase scientific literacy within local communities, enabling evidence-based decision-making. The following specific tasks supposed to be undertaken:

T1. Promote internal legal acts, regulatory and ethical expertise, RRI strategies in units conducting cohort studies

T2. Promote the supporting role of scientists in the creation of scientific projects by representatives of society

T3. Implement online and offline lessons to consolidate participation and interest in science among high school, pre and postgraduate students

T4. Implement RRI elements in study programmes

T5. Student involvement in the JoinUs4Health project

Promotion of RRI Strategies (T1) and RRI Elements in Study Programmes (T4)

Each participating university has been encouraged to adopt RRI strategies and incorporate them into their institutional policies and practices. This includes the development and promotion of internal legal acts, regulatory and ethical expertise, and the integration of RRI principles into university strategies.

In Rotterdam, a Bachelor-level course entitled From Science to Society was organised, which provided educational activities for 10 weeks in the areas of open science, science communication and public engagement. The course consisted of lectures and workshops, which were reflected in practical ways in group-projects posted on the JoinUs4Health platform.

In Greifswald, two facultative courses are offered, offering students a) to learn about the principles of RRI based on the EMC minor programme or b) explore the JoinUs4Health concept and methodology based on selected use cases.

At MUB, elements of the RRI are embedded in the development strategy, i.e. in particular a greater emphasis on including various parties who are not professionally involved in science in the co-creation of science. Moreover, it was proposed to the Medical Faculty Council to include new outcomes directly linked to RRI in the systematic of learning outcomes. This will allow RRI elements to be incorporated into many subjects already present in the course of education. In addition, some RRI elements, such as two-way science-society communication, were previously incorporated into subjects taught by the Bialystok PLUS team. Such changes, due to the procedural conditions of specific universities, may take several years (as they are spread over so-called educational cycles). Hence, their evaluation will only be possible over time. In addition, Bialystok hosted the Hackathon for Health, a competition for secondary school students, in which teams prepared concepts for social campaigns based on the results obtained from Bialystok PLUS. The winning team is in the process of preparing such a

campaign, which we will implement together in the coming months. The format proved to be an excellent way to roll out the idea of RRI based on a problem identified by a cohort study, obtain feedback from the population at risk, explore how to look at the problem and design a solution from it. Finally, this format provides an implementation that meets the public's expectations. Another example of promoting the project and strengthening the level of science literacy within the local community was the Research Café organised in Bialystok. The meeting included a discussion of the therapeutic effects of nature - forests, gardens - on people. The invited guests represented the world of professional scientists and practitioners directly connected to nature. The event was a great success and it was decided to organise it again, which is currently in progress.

Supporting Role of Scientists (T2)

Scientists at participating universities have been encouraged to support community representatives and collaborate with them in the creation of scientific projects. This partnership fosters mutual learning and enhances the relevance and impact of research projects. In-house and open meetings were held at all cohort centres to inform about the RRI opportunities materialising in the JoinUs4Health project. In Bialystok, a seminar for researchers was held during which the future development of the project was discussed. The platform also attracted the interest of the Polish Academy of Sciences, which declared its willingness to support the promotion of our tools among scientists. Further events are planned in the coming months of the project.

Online and Offline Lessons (T3)

To consolidate participation and interest in science, online and offline lessons have been implemented for high school, pre-, and post-graduate students. These educational initiatives aim to increase scientific literacy and encourage active involvement in scientific research. Part of the activities have been described in Task T1, but in the coming months activities for secondary school students will be prepared and implemented in Bialystok. The scenarios for these classes will be open and available to teachers so that they can educate themselves on RRI principles and assumptions in the future.

Student Involvement in the JoinUs4Health Project (T5)

Several students from participating universities have been actively involved in the JoinUs4Health project, including master and doctoral students. Their involvement has provided valuable insights and contributed to the project's objectives.

Implementation and Progress

Significant progress has been made in implementing science literacy initiatives and promoting university engagement. The following milestones have been achieved:

- Implementation of online and offline lessons for students
- Integration of RRI principles into study programmes
- Active involvement of students in the JoinUs4Health project

Next Steps

The project team will continue to support and monitor the implementation of science literacy initiatives, focusing on the following tasks:

- Ensuring the ongoing integration of RRI principles in university policies and practices
- Strengthening collaborations between scientists and community representatives
- Expanding educational initiatives to reach a wider audience
- Evaluating the impact of science literacy initiatives on local communities and decision-making

Conclusion

The implementation of science literacy initiatives within the JoinUs4Health project has demonstrated important progress in promoting RRI and increasing scientific literacy within local communities. Through the integration of RRI strategies and principles into university policies and practices, fostering collaboration between scientists and community representatives, offering online and offline lessons, and actively involving students in the project, the JoinUs4Health project has laid the foundation for greater understanding and engagement in scientific research. Moving forward, the project team will continue to support and monitor these science literacy initiatives, ensuring ongoing integration of RRI principles, strengthening partnerships, expanding educational opportunities, and evaluating the impact on local communities and decision-making. At the same time, it should be remembered that in a matter such as science literacy, the visibility of change is only possible after a long period of time. Hence, the activities carried out in our opinion contribute to the improvement of such parameters, but their unambiguous, parametric evaluation will only be possible after many years.

RRI and Rewarding System Integration

Introduction

In this section, we outline the progress made in implementing RRI and Citizen Science initiatives within the rewarding systems of research institutions involved in the JoinUs4Health. The aim is to consolidate the role of RRI in higher education and research and to create a more inclusive and collaborative research environment. The following specific tasks have been foreseen:

T1. Identify how to evaluate and reward researchers at cohort studies institutions in the consortium

T2. Develop a package of proposed solutions that can be implemented in universities

T3. Implement the rules (regulations for assessing and rewarding activity related to RRI)

T4. Promote implemented solutions among scientists

The task of implementing a system to reward researchers for participating in RRI processes is not easy. Firstly, the academic community has quite traditional and thoroughly established rules for evaluating scientific activity. It is based on a system of publishing research results, commercialising them, obtaining intellectual property rights or, finally, grants for research projects. Sometimes educational activities are additionally rewarded. It is therefore a hermetic and rather closed environment. It seems, therefore, that the formalisation of awards for RRI activities should be preceded above all by intensive promotion of such activities among scientists. The long-term goals of RRI should be explained and staff be educated on and made aware of the benefits of RRI before steps can be taken to formalise the change. Discussions in this area have been undertaken at the MUB, both at the level of the Dean of Faculty and the Vice-Rector for Student Affairs, in which the possibility of including RRI-related criteria in the current system of academic rewards has been raised. The authorities show an open attitude towards future changes in this area, but these must be preceded by the demonstration of practical examples of such projects. Worth noting is the change that is taking place in the Netherlands, where at national level the Dutch universities are shifting towards recognising engagement in their rewards system (see https://recognitionrewards.nl/), which should be seen as a progressive cultural change. Before the end of the JoinUs4Health project, meetings are planned with the authorities of universities or units conducting cohort studies, during which we will once again approach the possibility of creating or integrating into the existing system of rewarding researchers for participation in RRI projects

Conclusion

Implementing RRI and Citizen Science initiatives within the rewarding systems of research institutions involved in the JoinUs4Health project is a challenging but essential task. By focusing on identifying evaluation and reward mechanisms, developing proposed solutions, implementing regulations, and promoting these solutions among scientists, the project aims to foster a more inclusive and collaborative research environment. The process of formalizing rewards for RRI activities should begin with intensive promotion and education efforts among scientists to build understanding and support for the long-term goals of RRI. As discussions and meetings with university authorities continue, it is crucial to demonstrate practical examples of RRI projects and their potential benefits. In the future, the successful integration of RRI-related criteria in the current system of academic rewards will contribute to the consolidation of RRI's role in higher education and research.

Mutual Learning and RRI Support

Introduction

This part of the report refers to the progress made in implementing mutual learning and support for Responsible Research and Innovation (RRI) within the JoinUs4Health project. The project aims to facilitate two-way communication among stakeholders and provide training and support for RRI initiatives. The following specific tasks have were undertaken:

T1. Plan and implement question-answer communication functionality on the platform with predefined issue categories

T2. Develop and implement online courses (open education)

T3. Assess the feasibility of establishing RRI help desks at cohort studies institutions to develop initial action steps and recommendations for university authorities

Question-Answer Communication Functionality (T1)

A question-answer communication functionality has been successfully implemented on the online platform. Users can now highlight predefined categories of issues they would like to address, facilitating effective and focused discussions among various stakeholders. Of course, this is the technical dimension of this functionality so far, so it needs to be tested under conditions of higher traffic on the platform itself. It is assumed that on this basis it will be possible to improve and enhance this functionality.

Online/Offline Courses (T2)

At EMC the 10 weeks course (minor) entitled From Science to Society was organised. This minor focused on the changing definitions of scientific success, emphasizing the increasing importance of societal impact for a successful career in science. The course covered three key areas: science communication, open science, and citizen science. Through lectures, workshops, and project-based learning, students gained a comprehensive understanding of these topics and how they contributed to the success of research. Upon completion of the minor, students were able to apply principles of open science, science communication, and public engagement to boost the societal impact of scientific findings. The course featured a mix of teaching methods, including plenary sessions, interactive working groups, and problem-based learning projects. The minor had a broadening character and welcomed students from different faculties and universities, promoting interdisciplinarity and mutual learning. By combining competence education, coaching, self-study, and group work, students developed valuable skills and applied them in real-world scenarios. The know-how and materials from this course can now be adapted for similar projects in other cohort centers. By sharing the knowledge and resources gained during the course, students and educators in various locations can benefit from the insights and experiences, fostering the development of more interdisciplinary and impactful projects across different institutions. This will ultimately help to spread the principles of open science, science communication, and public engagement, further enhancing the societal impact of scientific research.

Feasibility Assessment for RRI Help Desks (T3)

At this stage, the concept of RRI is still not sufficiently well-established and widely recognized within the participating institutions to justify the creation of dedicated help desks. Further efforts to raise awareness, educate, and integrate RRI principles into the academic culture and practices are needed before the establishment of RRI help desks can become a viable and effective step.

Implementation and Progress

Reasonable progress has been made in implementing mutual learning and support for RRI within the JoinUs4Health project. The following milestones have been achieved:

- Implementation of question-answer communication functionality on the platform
- Development and implementation of online courses on RRI

Next Steps

The project team will continue to support and monitor the implementation of mutual learning and RRI support initiatives, focusing on the following tasks:

- Evaluating the impact of question-answer communication functionality on stakeholder engagement and collaboration
- An attempt to adapt and implement in other cohort centres the experience of the minor implemented in Rotterdam. These experiences should also be used in any RRI educational activities.

Conclusion

The JoinUs4Health project has made significant progress in implementing mutual learning and support for Responsible Research and Innovation (RRI). The successful implementation of the question-answer communication functionality on the platform has provided an avenue for focused discussions among various stakeholders. The development and implementation of the online courses, particularly the minor in Rotterdam, have demonstrated the potential for promoting interdisciplinary learning and the application of RRI principles in real-world scenarios. However, it is important to recognize that the establishment of RRI help desks is not yet feasible due to the current lack of widespread recognition and understanding of RRI principles within participating institutions. As a result, further efforts to raise awareness and integrate RRI into academic culture and practices are necessary. Moving forward, the project team will continue to support and monitor the implementation of mutual learning and RRI support initiatives. This includes evaluating the impact of the question-answer communication functionality, and attempting to adapt and implement the experiences gained from the Rotterdam minor in other cohort centers. The learnings from these experiences should also be incorporated into future RRI educational activities.

Communication and Dissemination: Knowledge Translation

Introduction

This section outlines the progress made in implementing knowledge translation as part of the communication and dissemination efforts within the JoinUs4Health. Knowledge translation aims to bridge the gap between academic research and public understanding by making scientific content more accessible and engaging. The following specific tasks have been conducted:

T1. Include in the design and functionalities of the online platform the possibility for users to vote/select their need for clarification of scientific issues

T2. Develop the main principles of knowledge translation for experts and their publication (distribution - also in printed materials)

T3. Evaluate the effectiveness of the actions taken (collecting feedback from the users of the platform)

Online Platform Functionality (T1)

The online platform has been designed and implemented to include the possibility for users to vote and select scientific content they would like to see explained in a more accessible manner. This functionality is a gateway into empowering people to work towards producing knowledge by collaborating with other community members helps identify the most relevant and interesting topics for the public. The voting system for issues presented on the platform allows the positioning of the most relevant issues of interest to users. It is also intended to increase the chances of setting up working groups on the platform, as it allows us to estimate how many people we could work with on a given topic.

Knowledge Translation Principles (T2)

A project has been implemented at MUB in which scientists who have published their article are encouraged to prepare a simplified description, targeted at those without a scientific background. At the moment, the content is posted on the MUB website, but eventually it could also be on the JoinUs4Health platform. All consortium members should decide this in unison. It is not easy, as the creation of content on the platform should be balanced so that there is no clear bias towards scientists instead of other stakeholders. The WP4 team will additionally develop a short set of tips on knowledge translation that every content creator should follow to increase communication effectiveness.

Evaluation of Effectiveness (T3)

No evaluation projects of the activities carried out have been initiated so far.

Implementation and Progress

In this group of institutional changes, not all of the tasks have been completed to date. However, some have been achieved:

- Implementation of the online platform functionality for selecting scientific content for knowledge translation

Next Steps

The project team will continue to support and monitor the implementation of knowledge translation initiatives, focusing on the following tasks:

- Preparation of guidance for researchers on the principles of knowledge translation and their practical application
- Continuously evaluating the effectiveness of knowledge translation efforts and making improvements as needed

Conclusion

The implementation of knowledge translation as part of the communication and dissemination efforts within the JoinUs4Health project should contribute to making scientific content more accessible and engaging for the public. By incorporating user feedback and refining the online platform functionality, the project continues to adapt and improve its approach to knowledge translation. Regardless, the intensification of efforts to popularize the principles of knowledge translation and their evaluation remain a challenge for the next period.

Final summary

It should be noted that many of the key institutional changes in the project will become apparent over time as the JoinUs4Health focal point demonstrates its planned effectiveness. Literally, higher level of interactions taking place on the online platform will result in more suggestions and topics being created and working teams forming to respond to them. This, in turn, will potentially generate both interest and greater input from various parties - scientists, local politicians, business, NGOs30. Thus, it can be concluded that institutional change is primarily a process, in which change is sought by undertaking specific activities, observing their impact and adapting to new conditions, more than a specific outcome meaning the achievement of an indicator. Above all, institutional change needs to be sustainable and grounded in the environment to which it is dedicated. At JoinUs4Health, we experienced the difficulties of implementing RRI within a reality that seemed familiar to us on a daily basis. We had to revise some of our assumptions, such as the one about a lot of grassroots activity by local community representatives on an online platform, understanding that stimulating citizen learning requires mutual learning, the sharing of knowledge, experience, intuition and feedback by each party. We believe that each of our experiences is a valuable lesson on the path of building societies that can use and co-create learning. These experiences remain transparent and should serve future projects that aim to add another brick in the construction of Responsible Research and Innovation in Europe.

Appendix

The following pictures show selected events described in the framework of this institutional change: