Join Us to Optimize Health Through Cohort Research

Benchmark methodology on implementing RRI and crowdsourcing for ongoing and future projects

Deliverable 2.2

Version 1.0

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Abbreviations

AIRR	Anticipation, Inclusion, Reflexivity and Responsiveness (key components of the RRI process dimension)
D	Deliverable
Erasmus MC	Erasmus Medical Centre
EUR	Erasmus University of Rotterdam
MUB	Medical University of Bialystok
RRI	Responsible Research and Innovation
UMG	University Medicine Greifswald

Summary

This deliverable builds on Deliverable 2.1 (D2.1) "Methodological guidelines on implementing RRI and crowdsourcing in cohort research for partners" to develop a methodology for responsible crowdsourcing. We begin by summarizing our initial proposal for the methodology, described in more detail in D2.1, and pose questions based on such initial proposal to ground our proposed revised responsible crowdsourcing methodology. We describe our revised methodology and provide our rationale for the key changes we made to its first iteration. We conclude by analysing why we were unable to test the methodology within the timeline of our project and provide recommendations for projects that might want to adapt and test our methodology in the future.

Where we started – our initial idea of a methodology combining RRI and crowdsourcing

This section provides a summary of the methodology as described in D2.1[1] as well as an analysis of its underlying assumptions and the ethical and methodological questions it raised, which provided the base for the reflection described in this document as well as the formulation of our proposed methodology.

Converging RRI and crowdsourcing[2]

Responsible Research and Innovation (RRI) provides a framework to open up the scientific process to the public, and to renegotiate the role of science in society. It fosters knowledge production processes that are responsive to societal challenges, through four main interconnected aspects. First, RRI promotes the democratization of knowledge-making, which translates to active participation of the public in science where stakeholders, including researchers, interact to set research agendas, produce knowledge and apply findings in local contexts (Reber, 2018). Second, RRI allows for iterative knowledge production, since it is in the interface of science, policy, and practice, allowing for greater potential for societal impact in a shorter time frame when compared to traditional scientific research (von Schomberg, 2019). Third, by involving societal actors, RRI increases the legitimacy of the knowledge making process as well as relevance and external validity of its results compared to conventional research, and thus can be a powerful tool to address the ongoing confidence crisis in science (Sutcliffe, 2011). Lastly, fostering a partnership between participants and scientists can increase participation in health research (Jagosh et al., 2012) and promote "scientific citizenship" not only among participants but also within local communities in cohort study regions, thus creating a more tangible local impact of cohort research.

Regarding RRI, it is important to realize that we are dealing with a shifting signifier. In recent years, two interpretations of RRI emerged, seen as complementary by some and as less compatible by others. On the one hand, especially the EU as a funding agency supported the introduction of five key pillars of RRI, focusing on operationalization: gender, ethics, open science, public engagement and science education, to which governance as a sixth key is sometimes added. Academic groups active in the RRI arena tend to focus more on the process dimension of RRI, so that the focus is on changing the way in which research was being conducted, eventually resulting in the AIRR concept, indicating anticipation, inclusion, reflexivity and responsiveness as key components of the process dimension of RRI (Stilgoe et al., 2013). The AIRR framework exemplified how RRI, after having been initiated in the context of European research policy ("top-down"), was adopted and further developed by the academic community ("bottom-up"). Recently, there is a tendency to replace RRI with the concept of open and responsible science. We cannot enter into a detailed discussion of these shifts, but it is important to be aware that RRI is not a fixed concept, but a dynamical and evolving one, taken up in various contexts and evolving in response to practice and experience. As will be explained in more detail below, however, the AIRR concept of RRI, which was developed more than a decade ago and was re-assessed as an "unfinished journey" in 2021 (Owen et al., 2021), is an important source of inspiration for our project.

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[1] https://zenodo.org/record/8170150
[2] This section contains text that was previously made available as a non-published pre-print manuscript (Barbosa Mendes et al., 2021). The manuscript can be accessed at https://osf.io/t47yh

RRI is an inherently deliberative methodological framework. This means that it relies on dialogue between different stakeholders for collective reasoning. While RRI has been operationalized in many different ways (Zwart et al., 2014), the co-creation process within RRI is often done in small groups of stakeholders, where deliberation can happen more effectively (this may involve innovative and imaginative settings, e.g. future labs, social labs, co-constructive design labs, science theatre, citizen panels, etc. (Zwart et al., 2017)). From a citizen's perspective, crowdsourced projects are easy to join and often do not require much preparation as comprehensive skills, advanced tools, and materials are not prerequisites for participation (Frigerio et al., 2021). With the advent of Web 2.0 technologies, the co-creation envisioned in RRI can be distributed, and a large number of people from diverse backgrounds can be involved in knowledge-making through crowdsourcing. By involving a larger number of people in the research process, crowdsourcing allows for addressing a wider range of research problems as well as increasing the speed in which challenges can be addressed (Franzoni & Sauermann, 2014). Moreover, it increases the potential for diversity of perspectives among the actors involved in co-creation and thus can allow for producing more socially robust knowledge (Nowotny, 2003).

To enable such distributed co-creation, the JoinUs4Health project developed a crowdsourcing methodology to operationalize RRI in health research and incorporate this methodology into three large, population-based prospective cohort studies. These cohort studies provide a particular potential to create living laboratories in the local cohort study regions and thus to develop and test our crowdsourcing methodology. Crowdsourcing has been defined as "using an online, distributed problem-solving and production model to leverage the collective intelligence of online communities to serve specific organizational goals" (Brabham 2013). Crowdsourcing applications have been grouped in various ways, e.g. human computation, crowd competitions, and peer collaboration (Hansson, Ludwig, and Aitamurto 2019) or microtasking, information pooling, broadcast search, and open collaboration (Blohm et al. 2017).

In its variety of applications, crowdsourcing has been evolving in recent years in the political, academic, and business area with increasing strives to become inclusive and interactive. In (bio)medical and health research, research-performing institutions have increasingly engaged citizens in searching for solutions to empirical problems (Wiggins & Wilbanks, 2019). Challenge contests or hackathons have also been used to collect ideas and possible solutions to issues related to health as well as promote mass engagement in specific health topics (Pan et al., 2017). Likewise, crowdsourcing has been used to increase data collection and analysis potential, where citizens are tasked with contributing data to answer a specific question (Franzoni et al., 2021). A shortcoming of such low-level engagement is the missed opportunity for more advanced and in-depth involvement in scientific processes – engagement often ends with the data observation, recording, and transfer to platforms or the scientific community (Frigerio et al., 2021).

In multiple areas of research, initiatives have been taken to make research more responsive to societal needs, and JoinUs4Health aims to apply the concept of open and responsible science to crowdsourcing projects. Crowdsourcing projects have moved towards involving citizens and stakeholders as more than data sources, collaborating with non-professional scientists in all stages of the research process (Peters & Besley, 2019). It is precisely here, we argue, that RRI can provide a useful framework in which crowdsourcing can be applied in a more responsible and inclusive manner.

RRI and crowdsourcing both opt for a systemic holistic perspective and combine retrospective perspectives (learning from experience) with prospective ones (exploring scenarios).

Crowdsourcing reflects the urgent need to transform our methodologies on the basis of "collective thinking" (Schauer, 2018), while RRI implies that societal actors work together during the whole process in order to better align its outcomes with the values, needs, concerns and expectations of society (von Schomberg, 2019). Since the applied crowdsourcing methodology allows involving non-professional scientists not only in data collection but also in all steps of the scientific process, including protocol validation and the formulation of research questions, it can be considered as a radical and intense form of citizen science (Haklay, 2013).

One of the challenges in operationalising RRI through crowdsourcing is that deliberative practices are central to RRI (Pellé, 2016), and these practices need to have sufficient quality to produce usable knowledge. RRI methodologies often rely on close interactions among epistemic actors to ensure that co-creation is achieved through deliberation (Deserti et al., 2022). Actors are expected to contribute to co-creation from their position as situated knowers, where their previous experiences, identity, and background have an important effect on the knowledge that they contribute to the research process. However, such close interactions are not possible within a large community of people. Crowdsourced interactions are by nature depersonalised, where deliberation focuses on viewpoints rather than actors (Aitamurto, 2016). Arguments can be proposed by specific actors and taken up by others, and anonymity in the crowdsourcing process blurs the understanding of how positionality influences the arguments proposed.

On the other hand, crowdsourcing allows for gathering input from a large number of people. Even though the publics involved in crowdsourcing processes are often not representative of the stakeholders in a given issue, the diversity of opinions expressed in such processes tend to represent the opinions expressed by these larger publics (Aitamurto & Landemore, 2016). Moreover, since crowdsourcing is facilitated using Web 2.0 technologies, it enables asynchronous and displaced interactions, where people from any location and background can contribute as much or as little as they choose, at any time that suits their availability.

With the aim to foster these deliberative processes while still making use of the advantages of crowdsourcing as a knowledge production method, we devised a methodology that connects consultive mechanisms that are typical in crowdsourcing with deeper co-creation processes in smaller groups to enable different scales of collaboration between members of the community.

The initial mechanics of the methodology and its underlying assumptions

Traditionally, crowdsourcing includes four elements (Brabham 2013):

1) an individual or an organization has a task (questioner),

2) a community addresses the task (crowd),

3) a platform enables the task to be addressed and crowd members to interact, and

4) a benefit arises for both the questioner and the crowd. In our initial methodology.

We proposed a set of key features of a responsible crowdsourcing approach suitable to promote RRI and mutual learning. Figure 1 outlines the basics of the underlying concept and Figure 2 highlights the features of our proposed methodology that differ from the traditional approach to crowdsourcing. Features of this approach were first proposed to bridge the gap between science and public health (Schauer, 2018), but are in principle applicable to any research field.

In our initial iteration of the methodology, any member of the community could act as the crowdsourcer (suggesting questions / tasks) or crowd member (vote; contribute time or knowledge). Suggestions could comprise a variety of aspects such as research questions to be investigated, questions relating to existing knowledge or real-life experiences, indication of information needs, offers or others. Tasks referred to specific actions, for which input is sought from the online community. Examples of tasks are invitation to other stakeholder groups to review manuscripts prior to submission (questioner: scientist), requests for a literature review (e.g. business representative) or translation of published research into citizen-friendly language (e.g. citizen).

Submitted suggestions (questions / tasks) would be screened by community members and categorized before being collated in a search database to facilitate ease of navigation, manage metadata to allow tagging, cluster similar suggestions together and optimize data quality. Community members could screen suggestions via search and filtering functions, promote suggestions by submitting their support (vote) or comments (reviewed by community members before being made public) and express willingness to contribute time to help addressing a given question or task. Such activities (submissions, screening, voting, indicating willingness to contribute) were termed "community-level interactions" as at that stage no direct exchange takes place between community members (no forum dialogue). Volunteer reviewers or assigned "Facilitators" (any platform users who wish to facilitate a team – no prior experience required) could provide relevant background materials (e.g., available research, further information) or revise and summarize comments by community members.

Since it is not possible to address all proposed questions, a transparent process would need to be applied to select questions via community-level interactions described above. For instance, community support (votes, resembling "Microtasking" as described by Blohm et al. (2017)), the number, skills and diversity of volunteering individuals and the availability of a "Facilitator" could be taken into account.

The proposed process required first a volunteer to create a topic based on the suggestion to be promoted. Any community member could turn a suggestion into a topic but needed to agree with a set of guidelines and outline a plan, which is opened for community feedback for two weeks to collate comments and start recruiting volunteers. If no objections are raised, a team would be formed from the group of volunteers given that a primary "Facilitator" takes care of

the team, and a "Moderator" has been assigned to act as main contact point and oversee the process.

Once a working team has formed, team members may interact directly (team-level interactions). The assigned primary "Facilitator" is responsible for coordinating the team and ensuring standard reporting of plans, progress, and outputs. Teams could apply various approaches to their projects.

For instance, at an exploratory stage, focus group discussions or a Delphi questionnaire methodology could be used to explore key points related to the question of interest and develop a research proposal specifying tasks and roles. Tasks would subsequently be addressed via direct exchanges (virtual meetings, discussions with stakeholders, review etc) ideally breaking down larger tasks into smaller activities so to offer a circumscribed time of commitment. Such team-level interactions match the crowdsourcing types "Broadcast Search" and "Open Collaboration" (Blohm et al. 2017). Working teams will frequently require information to be reviewed. Tasks like this can be outsourced to the community by creating a "Task" on the platform if the working team itself does not include sufficient volunteers or expertise (resembles "Microtasking" as described by Blohm et al. (2017)).

In summary, in our initially proposed methodology we attempted to follow the principles of RRI that advocate for horizontal mutual learning processes. We envisioned that crowdsourcing could be initiated by both organisations and individuals. We did not wish to exclude actors that are not affiliated with organisations or interest groups from proposing tasks for the JoinUs4Health community to address, but rather welcomed contributions from a variety of actors.
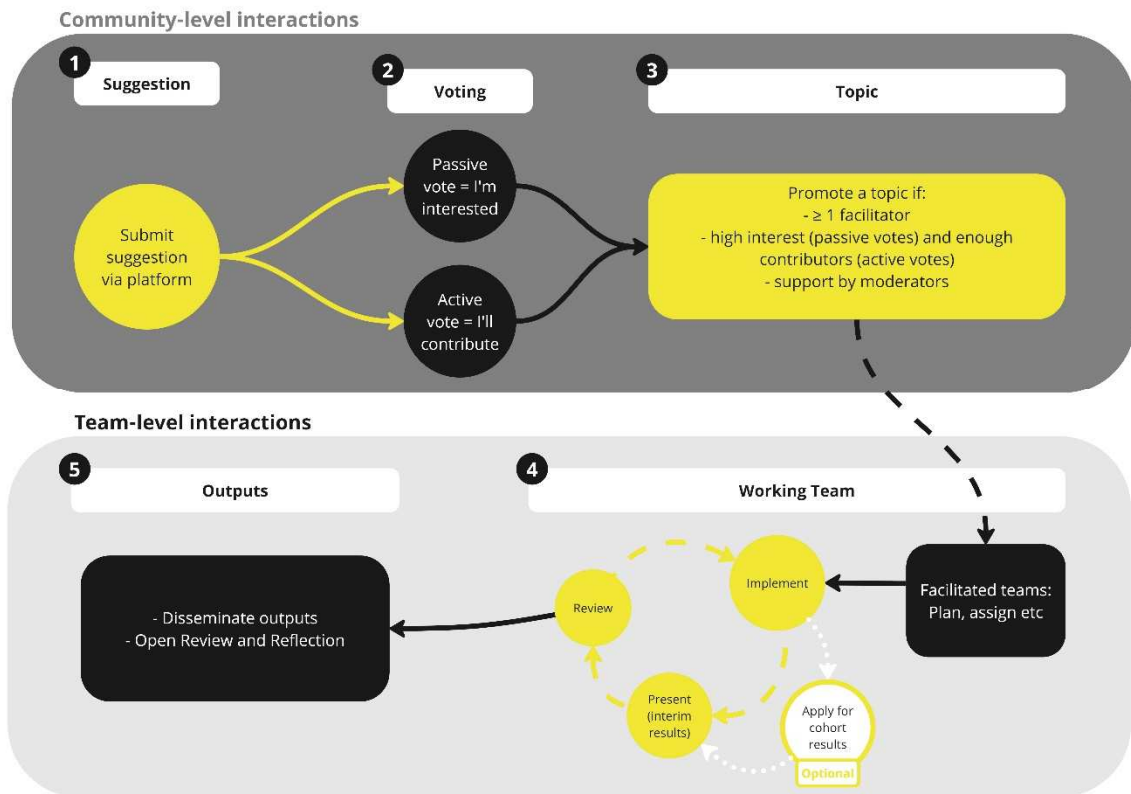
Figure 1 - initial schematics of the responsible crowdsourcing methodology
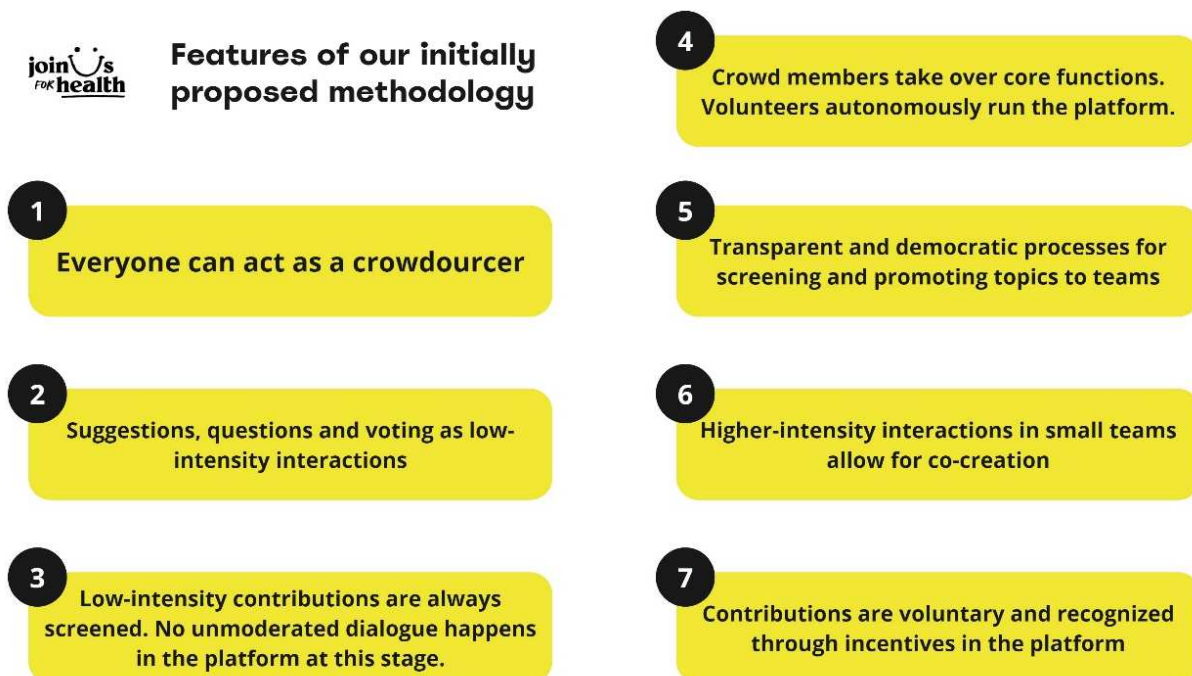

Figure 2 - Features of our initially proposed methodology

Ethical and methodological considerations as a starting point for reflection

Throughout our work in the project, the initially proposed methodology was discussed within our consortium, with external stakeholders and with our advisory panel. During those discussions, several questions emerged that needed to be addressed in the process of further developing our methodology.

Since the aim of our project is to combine Responsible Research and Innovation (RRI) and crowdsourcing as converging approaches to promote inclusive innovation and citizen engagement in cohort research, we begun by reflecting on how appropriate the features of our methodology were in incorporating the dimensions of RRI. In our project, we ascribe to the process or AIRR definition of RRI as explained above, proposed by Stilgoe, Owen, and Macnaghten (2013), which defines RRI as "taking care of the future through collective stewardship of science and innovation in the present" (p. 1570). The authors define four process dimensions of RRI: Anticipation, Reflexivity, Inclusion, and Responsiveness. Anticipation encourages researchers and organisations to think systematically about the consequences of their research. Reflexivity refers to institutional reflexivity rather than only individual reflexivity, where value systems and theories that shape how research is conducted are critically examined. Inclusion refers to including voices of stakeholders and the wider public into a deliberative process where voices that are not normally included in the knowledge making process can be heard. Responsiveness is about "adjusting courses of action while recognising the insufficiency of knowledge and control" (Stilgoe, Owen, and Macnaghten 2013, p. 1572). We use the AIRR framework as a starting point to tap into political aspects of research and innovation and through that reflection discuss issues of (social and epistemic) justice in research and innovation (Ludwig & Macnaghten, 2020) as it relates to our methodology.

We had indicated in our previous deliverable (Zwart et al., 2021) that we were committed to foster social and epistemic inclusion in our platform. One of the features to enable such inclusion was the ability for anyone to contribute to the platform's knowledge base, not only as a contributor but also as a crowdsourcer and facilitator. This would allow people from varied backgrounds to contribute their knowledge, which could originate according to their positionality, and give space for projects anchored in these types of knowledge to emerge in the platform. We were open to suggestions and welcomed other knowledge than scientific knowledge. For example our involvement with activities such as gardening for health, forest bathing, Health University, and online workshop series with public health authorities, intended to combine scientific and societal knowledge. Overall, however, we tended to focus on the sharing and requesting of scientific knowledge.

Most of the contributions we have seen in the JoinUs4Health platform either requested more information on work being done in a scientific project (e.g., feedback on existing results from the cohort studies) or requested scientific evidence about a specific topic. This underlined our difficulties in getting the general public to register and interact in the platform. However, some of these contributions came directly from members of the general public through in-person events organized by our project team, indicating a willingness of people who might not have scientific training to engage with scientific knowledge in a citizen science project. While we valued these contributions, the challenge of epistemic inclusion is to provide space and conditions for de-centring scientific knowledge and creating a community where other types of knowledge would be equally valued. In principle, everyone had an equal opportunity to use the portal. Given the fact that most users represented a demand for science-related knowledge, to foster epistemic inclusion, a more proactive approach would strengthen the

effort, e.g., contributions starting from experiential or traditional knowledge, for example, should then be more actively encouraged.

A key feature of both reflection and anticipation in RRI is that it is meant to be done collectively and through co-creation with all stakeholders, to ensure as many interests as possible are contemplated in the research process (Jansma et al., 2021). When thinking about anticipation and reflexivity, which are inextricably linked together in the RRI dimensions, and how these dimensions relate to our methodology, we wondered if our co-creative processes were embedded enough to foster both dimensions in our knowledge-making processes.

As we initially envisioned, the initial contributions in the platform were not meant to be debated in the platform without moderation. In our view, free dialogue could promote undesirable behaviour that could compromise the safety of the community members in the platform. Additionally, we believed that deliberation in this stage could be detrimental and result in loss of information (Solomon, 2006), as we envisioned that the initial contributions would constitute a large, complex, and diverse database of ideas that could be used for any of the community members. The intention was to provide a "safe environment" would have meant that suggestions or comments that are abusive or indicative of misleading information, fake news or similar would have been held back at least temporarily. The intention was to a) either discuss such suggestions with advisory boards to gather their perspective and make a decision accordingly or b) allow users to form a team to discuss such suggestions / comments before making them public. On the other hand, although the creation and maintenance of a safe environment for deliberation is an important condition for open communication as advocated by Habermas and others, there is nonetheless a tension with the ideal of co-creation which relies on deliberative dialogue focused on mutual learning, particularly a dialogue that is reflexive about the dynamics that arise in such exchanges (Valkenburg et al., 2020).

Lastly, we considered responsibility and reflexivity as aspects of our methodology that were embedded in our collaboration with the cohort studies. Cohort studies produce large amounts of data that often go unused due to limited capacity for executing research. Like many citizen science advocates, we hoped that citizen science could help us increase our research capacity (Kimura & Kinchy, 2016) and such increased capacity would result in more knowledge being produced and thus have societal impact. More than being large producers of data and scientific results, cohort studies are long-term research studies that are embedded into local communities, often following a slice of the local population in a specific region for decades and therefore producing knowledge that is of high relevance for that region. Due to that close relationship with local communities, there is untapped potential for mutual learning, where cohort studies would take up the concerns and opinions of local communities into account.

Our methodology established a pipeline and a procedure for working teams to use crowdsourcing platforms in cohort research. We experienced that such a process can have benefits for cohorts, e.g., increased willingness to participate in cohort examination (higher response) or could lead to recommendations of what types of input could be collected in the future efforts. Initially, it was difficult to predict what to expect, but on the basis of our project experience working teams could specify the options of platform use in cohort research more concretely.

Revisiting the schematics of responsible crowdsourcing

To address the questions and issues raised in the previous section, we propose here a revised methodology for responsible crowdsourcing. We summarize the updated features of the responsible crowdsourcing methodology in Figure 3 and provide the schematics of the methodology's mechanics in Figure 4.

Updated features of the Responsible Crowdsourcing Methodology

1. Users contribute health stories instead of questions or suggestions

2. Anyone can be an original contributor or initiate a knowledge-making proposal, prioritizing experiential knowledge

3. Members can vote on contributions, but those votes do not determine if the contribution is promoted to a topic

4. Knowledge-making proposals are co-created between people who voted to contribute and the initial proponents

5. Cohort results can be used by teams but should not be the only source of evidence in a knowledge-making project

Figure 3 - Updated features of the responsible crowdsourcing methodology

In an attempt to de-centre scientific knowledge and foster epistemic inclusion, we propose that responsible crowdsourcing starts with users sharing health stories on the platform.

What is a health story?

Stories are commonly defined as a narrative sequence of events that has a beginning, middle, and end. There are not much restrictions in terms of format, but they have a common purpose which is sharing experience.[3] From the perspective of epistemic inclusion, experiential stories have the potential to contribute to epistemic co-construction, meaning people use them for sense-making of their experiences and for naming, analysing and negotiating power structures and relationships in health beliefs and practices. On the platform, contributors can tag their

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stories according to the themes that they think their stories explore. Once health stories are posted, the wider community can cast votes to signal that they find that contribution interesting (passive vote) or to signal that they would be interested in joining a team that would work on investigating the topics related to that contribution (active vote). In the previous iteration of the methodology, only contributions that had a sufficiently high number of votes would be then promoted for a topic, at the discretion of the community moderators. However, relying on number of passive votes for promoting contributions to knowledge-making projects might impair the take-up of marginalized perspectives. Therefore, we propose that promoting a contribution (or a set of contributions) to a knowledge-making project would depend on the amount of people that would be willing to actively contribute to drafting a proposal or the project work itself, which also guarantees that contributions would not be promoted without sufficient support from the community.

It is important to say that the user that posted the original idea is always assumed to be a contributor for the team, should this be turned into a project. They are free to excuse themselves if they do not wish to participate, but they are always offered the possibility to do so. On one hand, it is important that the original author of the contribution is able to elaborate on their perspective through working on a proposal and a team-led project. On the other hand, we do not wish that contributors feel obliged to take part in more intense collaboration in the platform if they feel like they are unable or unwilling. Therefore, by allowing original collaborators to indicate they would not wish to contribute to any project that their contribution might inspire, we still allow for flexible participation in the platform.

Once contributions have active votes, a knowledge-making project proposal can be prepared for submission. This short proposal would include a brief rationale for the project (including how the project relates to the original contribution), a short reflection on how the project is supposed to be approached, which people should the team reach out to and what kind of knowledge they might be missing to execute the project. We will encourage that the proposal is not formulated only by one individual but rather co-created by the active contributors of a suggestion, including the original author of the contribution when appropriate. In this co-creation process, we propose that the cohort institutions as well as more experienced users in the platform offer methodological and ethical support to ensure that the approaches used by the teams incorporate co-creative practices and abides by ethical standards. This will be further developed in our deliverable on factors affecting engagement and uptake of RRI in cohort research (D2.3).

The proposal co-created is then submitted for review by a moderator, who would be an experienced user in the platform that volunteered for the role, as well as made available for the wider community for comments. Once both the moderator and the community have no further suggestions to the planned project, the working team is then formally assembled. The working team can be comprised of the people that signalled initially that they want to contribute, or the team can recruit other members from the community in the platform and may reach out to networks, initiatives, individuals or groups that may be interested in contributing. The size of the team will be determined by the nature of the project and the tasks that need to be executed. If a cap on participants is necessary, the moderator may help with a selection process to maximize diversity in accordance with the perspectives that the project needs to have represented. These perspectives can also be integrated through consultation with stakeholders from outside the team if they are not available within the pool of volunteers.

Once the team is assembled, the team members will work together to execute the planned project in the time frame that was determined in the proposal. It is important that the projects are self-contained and have short time frames (preferably a month or six weeks, cf. D3.1:

encouragement but no time pressure). Shorter time frames allow engagement to be maintained and maximizes sense of reward for team members since they can see the result of their work not long after they started collaborating. During their work, teams are expected to keep an open line of communication with the other community members. They can ask for specific contributions from the community via Tasks, as well as feedback on their interim results and their approach. This collaboration provides an opportunity for the wider community to be involved in the work the teams are doing, even if they do not have the availability to join a team. It also allows for a wider variety of perspectives to be integrated into the work the teams are performing.

Collaboration is also possible with the cohort institutions, particularly in the form of requesting the preparation of results tailored to the topic or methodological consultation (Cf. D4.2). Teams can request aggregated results from the cohort studies, which will form one of the sources of information, which the team can integrate into their project. The cohort institutions can offer methodological support to ensure that teams use methods that foster that knowledge integration of scientific knowledge with other types of knowledge.

Once their proposed short project is completed, the teams make available their learnings to the community in the platform and have the option to propose a new follow-up project. These follow-up projects should always be proposed with the option of other people joining as contributors. Other people, who were not part of the original team, might also propose projects based on the team's learnings, thus promoting cross-fertilization (Gimpel et al., 2020). They are encouraged to post their experiences and learnings, perhaps merely as suggestions, but preferably as stories, thus giving back to the community knowledge base. The rationale behind encouraging stories is, as indicated, that in principle they offer more opportunities for co-construction and epistemic inclusion across knowledge forms. The outputs generated by the teams can also be fed back into the cohort studies, where it could e.g. inform procedures, content of investigations, research questions or methods of dissemination. The uptake of the knowledge generated is a key aspect of the reciprocity principle embedded into the platform.
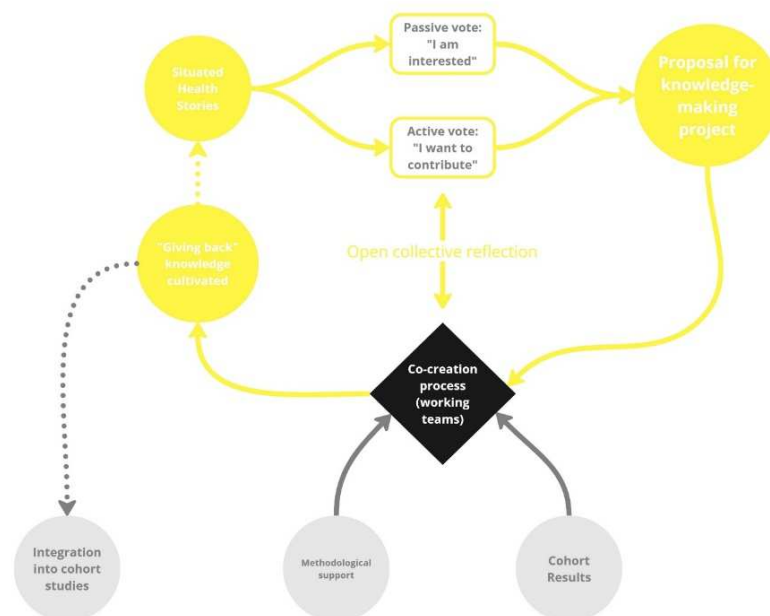

Figure 4 - Schematics of the responsible crowdsourcing methodology

Rationale for the revisited methodology

Our initial proposal for the methodology had a broad scope, envisioning the platform as a one-stop shop for collaboration between stakeholders on all matters relating to health. That would encompass educational activities, science communication, science-based community initiatives, and others. However, for this deliverable and for the purpose of methodological development, we chose to narrow the scope of the updated methodology to encompass only activities with a knowledge-making purpose. Knowledge-making in this context means producing validated knowledge through specific systems of knowledge, not necessarily scientific ones (cf. Wiggin and Crowston 2011, DOI: 10.1109/HICSS.2012.295). Our rationale was both conceptual and practical in nature: our project understands RRI as a set of practices to make research and innovation more responsible and responsive to societal needs, and even though these practices can encompass other activities beyond knowledge-making, the epistemic practices are still central to the RRI approach. Therefore, we decided to focus on the knowledge-making goals of RRI and use our methodology as a tool to pursue those goals.

Since we hoped that our methodology would be a tool to implement knowledge-making through RRI, we reflected on what kind of knowledge should be produced. In our previous deliverable, we outlined that the original contribution could consist of "invitation of other stakeholder groups to review manuscripts prior to submission (questioner: scientist), requests for a literature review (e.g. Business representative) or translation of published research into lay language (e.g. citizen)". These examples highlight possibilities for crowdsourcing labour that would be performed in a particular research (or research-adjacent) project, but the question is: do they offer possibilities for crowdsourcing knowledge itself from the participants. The reason for such requests could be a request by a team for instance to support their work (e.g. online workshop series with public health officials) or providing the opportunity for citizens or other groups to provide feedback on a manuscript before publication.

Public engagement in RRI aims to integrate perspective from the involved stakeholders into the knowledge-making process to produce more robust and societally relevant knowledge (Nowotny, 2003). The potential of crowdsourcing relating to its use as a tool for implementing RRI lies on its ability to access "collective wisdom", where different perspectives are integrated to produce more comprehensive knowledge (Jane Budge et al., 2015). Therefore, we decided that our methodology should enable crowdsourcing of these different types of knowledge, brought into the platform by people from varied backgrounds.

More specifically, we wanted to focus on crowdsourcing knowledges that are not traditionally represented in scientific research. Citizen science is not meant to be an extension of institutionally-embedded academic science (Kimura & Kinchy, 2019), where non-professional scientists would provide scientific evidence in a decentralized manner. Rather, citizen science (and by consequence crowdsourcing) involves a recognition of different forms of expertise and an expectation that these variety of expertise would be represented in a citizen science project through the inclusion of actors with multiple backgrounds (Jaeger et al., 2022) (cf. D7.1). Therefore, the knowledge making process should encompass a broad scope of contributions, e.g., questions for information, suggesting questions for research up to sharing experiences in the form of stories. Requesting information or suggesting research questions is a way to engage, inviting researchers to formulate research questions in response, but if participation would be limited to that, the methodology would run the risk of prioritizing scientific knowledge over other types of knowledge. Encouraging users to contribute (research) questions or suggestions could have privileged users that have prior training in and knowledge of scientific methods (Beck et al., 2022). As indicated, it is essential that our methodology also encourages other (more experiential or narrative) formats.

Therefore, we wanted to ensure that initial contributions would allow those different perspectives to be visible. For this reason, we adopted health stories as our starting point. We chose to use stories as a starting point because stories can help one make sense of their own experiences while also allowing for both the storyteller and the listener or reader to connect such experiences with the experience of others (Baillergeau & Duyvendak, 2016; Tonelli & Shapiro, 2020). Stories would also situate the contributed knowledge in the platform by providing enough contextual information for others to relate to the contribution from the perspective of the original poster. By using stories as a starting point, we invite people that would have otherwise come into the community as a representative of their professional group or organization, for example, to provide a more embodied and situated contribution and thus allowing for anyone, regardless of their affiliation to an institution or organization (or lack thereof) to make a meaningful contribution to the knowledge base in the platform.

Additionally, we chose to disconnect the number of passive votes to the progression of an initial contribution to encourage contributions that might not have wide interest in the community to still be developed into proposals if enough community members are willing to actively support it. Our platform has the potential to be a site for performing undone science (Ottinger, 2017), in other words research that starts from the needs of marginalized communities that would otherwise not be performed in an institutionalized context of academic research. Thus, by allowing topics and working teams to be established based on contributions that might not have much visibility in the platform, we provide a space for development of projects that could have a relatively low interest from the community but high active engagement from community members that could benefit from such projects.

We recognize that by decoupling passive votes from the establishment of working teams, we also open space for the creation of epistemic bubbles, where projects that represent exclusively niche and narrow perspectives could be proposed and executed. Therefore, to mitigate such risks we encourage the co-creation of the knowledge-making proposal between the initial contributor on which the proposal is based and the community members that signal they would like to actively contribute to the topic. This co-creation process would be transparent and would take place through comments in the platform, where early drafts of the proposal would be available also for contribution from other members of the community that are not willing to contribute to the execution of the project itself.

In fact, co-creation is a key element of RRI and consequently of our responsible crowdsourcing methodology. We strive for encouraging co-creative approaches in the working teams whenever possible, where knowledge is understood as plural. In order to foster knowledge plurality, we make available cohort results not to be used as a single source of information to answer the questions that the working teams pose in their projects. Rather, we encourage teams to integrate scientific evidence with other types of knowledge, by supporting teams that use cohort to combine it with knowledges from other traditions through methodological mentorship offered by cohort institutions.

Our suggestions for methodological innovations have yet to be tested

We were not yet able to test out the methodological innovations outlined in the previous section. Deliverable 7.4 ("Experiences as a consortium") outlines some factors that may have contributed to the low level of engagement to date.

One of the determining factors of our difficulties in testing methodological innovation was the lack of a user base in our platform. We ran into issues during development, which delayed the launch of our platform and therefore delayed our engagement and advertisement efforts. While we had some initial engagement, especially derived from our in-person events, we did not have enough active or passive contributors in the platform to take up suggestions and questions that were posted in the platform and engage in a co-creation process. Not all suggestions can be taken up, only those suggestions that are endorsed by enough contributors to make interactions worthwhile.

We believe one of the issues with our lack of engagement was our broad scope in terms of goals and activities of the platform and the communication of that scope to possible contributors to the platform. Recurring feedback we got from potential users was that they did not understand what kind of contributions were expected from them once they registered, or what would happen with their contributions after they were posted in the platform. Moreover, it became evident after we proposed the initial methodology that our partners within our consortium had diverging ideas on what RRI consisted, the role that RRI had in the project and how it translated into the methodology. Therefore, given the fact that partners came from different backgrounds and brought in different perspectives, creating common ground within the project proved a time-consuming effort that delayed our engagement efforts because we could not anchor them into common goals and approaches.

Additionally, the project, the platform as well as the methodology, were planned and established without public engagement. This is the case in many RRI-inspired project. They aim to foster public engagement and co-creation, but the tools to do so are developed by the consortium. If we take RRI seriously, we believe this practice is open for reflection. How to involve societal voices also in the development of tools such as crowdsourcing platforms? Our platform was conceptualized from a need expressed by the cohort institutions involved in our project, but we had little insight into what the needs of potential users were. Our motivation for engaging in co-creation was precisely to find out what the needs and concerns of potential users were. But to do so adequately, we propose to build co-creation also into the development process of RRI tools.

Nevertheless, despite not having had the possibility of testing our methodology, we believe it is solidly grounded in RRI and citizen science theory as well as in our experiences as a consortium. We hope that our lessons learned and our suggestions for methodological innovation will be taken up, adapted, and tested by future projects that share our ambitions of making (health) science more responsible and inclusive.

After the end of the project in December 2023, we will continue to run the platform and website for at least three more years, which gives us continued opportunities to build a more active platform community and thus test our revised methodology. Furthermore, the JoinUs4Health platform will be open source and can thus be implemented by other actors (institutional or societal) and modified according to the settings. Therefore, the concept, platform and methodology can be refined and tested also in other contexts.

For projects wanting to establish their own RRI tool, we recommend that:

- they co-create their platform and their adapted methodology with potential users from the beginning of the project (for an example on how that co-creation could be operationalized, see (Molla et al., 2018)) and continue to do so iteratively throughout their project.
- time is allowed to create a common language and vision between project partners to ensure the manner in which the methodology is adapted into the project's context realizes the shared goals in the project consortium.
- future projects embedded their testing of the methodology into a structure of responsibility within institutions involved in the project, where stakeholders already embedded in knowledge-making within these institutions engage in mutual learning through the methodology, and the knowledge produced using such methodology is promptly integrated by these stakeholders.

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