



## Join Us to Optimize Health Through Cohort Research

Deliverable 2.1 Methodological guidelines on implementing RRI and crowdsourcing in cohort research for partners

Version 1.0

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**Contents**

Abbreviations ..... 3

Summary ..... 4

1 Introduction..... 5

2 RRI, citizen science and crowdsourcing..... 6

3 Epistemic inclusion ..... 7

4 Cohort research ..... 8

5 Crowdsourcing..... 9

6 Key Features ..... 11

    6.1 Everyone can act as questioner or crowd member ..... 11

    6.2 Low-level interactions via an online platform ..... 11

    6.3 Crowd members take over core functions ..... 11

    6.4 Democratic process with option of crowdfunding ..... 12

    6.5 High-level interactions via teams ..... 12

    6.6 Science-based best practice approach..... 12

    6.7 Maximum automation ..... 12

    6.8 Inclusiveness..... 12

    6.9 Voluntary contributions coupled with recognition and incentives..... 13

7 Caveats ..... 14

References..... 15

**Abbreviations**

QH: Quadruple Helix

RPO: Research Performing Organisation

RRI: Responsible Research and Innovation

## Summary

Responsible Research and Innovation (RRI) and crowdsourcing share several features, but the link between these methodologies remains underexplored. The aim of this deliverable is to illustrate the emergence of participatory research, convergence and RRI and describe key features of the JoinUs4Health concept combining RRI and crowdsourcing as converging approaches to promote inclusive innovation.

We notice a trend towards convergence in research on various levels. In Europe, building on previous developments, this culminated in RRI. Three stages can be identified in RRI from conceptual developments, via the identification of RRI keys or pillars, down to the current pragmatic turn, focussing on the development of concrete tools for practicing, implementing, and facilitating responsible, participatory and anticipatory research.

We propose a set of key features to converge RRI and crowdsourcing: Everybody can act as questioner or crowd member. Questions or tasks are collated in an online database. Crowd members can vote on questions and indicate their support (low-level interactions). If a question or task has received sufficient votes and contributors, it is addressed via teams (high-level interactions). Coupled with best practice guidelines and strategies to promote inclusiveness and effective dissemination, we postulate that this concept can make research and innovation more engaging and inclusive.

# 1 Introduction

Triggered by the pressing societal challenges we are facing, drastic changes are taking place in the way in which scientific research is designed and conducted. Research methodologies are rapidly evolving, as research aspires to become more collaborative, inclusive and interactive, more sensitive to societal expectations and concerns, and better equipped to effectively address urgent and complex societal needs. Besides intense collaborations across research performing organisations and across disciplines and fields, this involves interaction with society at various levels, not only during the implementation stage, but as an inherent dimension of the research trajectory as such. Within the European context, this latter development is often referred to as *Responsible Research and Innovation* (RRI). In principle, RRI has radical implications for the ways in which research is conducted and for the future development of research methodologies. RRI is currently experiencing a pragmatic turn, putting concepts into practice, and this deliverable outlines how crowdsourcing offers concrete methodological opportunities to enable this trend towards interdisciplinary collaboration, inclusiveness and societal interaction.

Three stages can be distinguished in the development of RRI, we argue (Figure 1). RRI discourse began with general definitions and conceptions (first stage), resulting in the AIRR concept, focussing on anticipation, inclusion, reflexivity and responsiveness as key components of the *process* dimension of RRI. The second stage gave rise to the identification of *particular pillars* of RRI, identified as the five RRI keys (gender, ethics, open science, public engagement and science education), to which governance as a sixth key is sometimes added. The third stage focusses on the development of *concrete* tools and indicators for practicing, implementing, monitoring and evaluating RRI.

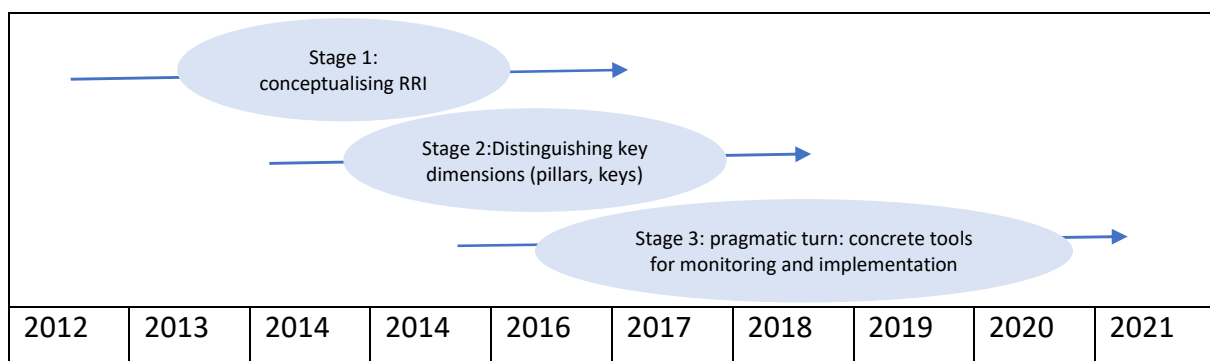


Figure 1. Overview of RRI stages.

Currently therefore, during the “third stage”, we notice a pragmatic turn in RRI discourse (exemplified by projects such as RRI Tools and RRI Practice),<sup>1</sup> moving away from conceptual debates and focussing on concrete methods and tools to foster interactive and inclusive innovation. In contrast to the deficit model, the focus of RRI is on knowledge and experiences available in society and relevant for innovative research. The goal is to further positive societal impact by exploring possible scenarios and to co-create the future.

<sup>1</sup> <https://rri-tools.eu>; <https://www.rri-practice.eu>

## 2 RRI, citizen science and crowdsourcing

*Responsible Research and Innovation* and crowdsourcing share several features, e.g. the aim to foster inclusive innovation, collective intelligence, mutual learning, diversity and cross-fertilization. Participatory research is in vogue and currently emerging under various closely related labels (RRI, Open Science, Citizen Science, crowdsourcing and the like), building on the conviction that knowledge deficits can only be addressed through collaboration, not only across disciplines, but also with participants from outside academia (citizen scientists). However, in the published literature, while the link between RRI and citizen science has been discussed more often (Smallman 2018), the link between RRI and crowdsourcing has rarely been drawn. Citizen science is the oldest concept, building on an impressive tradition, and can be defined as scientific work undertaken by members of the general public, in collaboration with and under the direction of professional scientists and scientific institutions. Citizen science may be performed by individuals, teams, or networks of volunteers. Interestingly, William Whewell (1794-1866), who invented the word “science”, is also credited with coining the term “citizen science” and with organising what is now considered as one of the first paradigmatic citizen science projects, mobilising hundreds of volunteers internationally to study ocean tides. Another field with a long track record of participatory research (citizen science) is meteorology. Meteorology developed vast networks of meteorological stations, so that all the world became a meteorological laboratory. After a period of professionalisation, research is again highly dependent on input from outsiders. Science requires distributed intelligence and participatory methodologies for data collection. While the neologism “science” was introduced as a decidedly exclusive concept (excluding lay knowledge, but also the humanities for instance from the arena of science), Whewell apparently was already convinced that a complementary approach was needed as well to make it work, especially when facing complex issues (from understanding ocean dynamics to human health).

What are the specific characteristics of crowdsourcing compared to citizen science? As indicated, citizen science is a much older concept, and can generally be defined as distributing specific scientific tasks (e.g. meteorological measurements, counting birds or insects, etc.) to lay persons, i.e. non-professional members of the public, acting as volunteers. Crowdsourcing is a more recent term and involves the use of online platforms to collect ideas, questions, solutions and concerns of “crowds” (i.e. relatively large and not strictly defined groups of participants) by breaking complex tasks into microtasks (Van Etten et al 2016). Crowdsourcing aims to offer a concrete methodology for engaging citizens in research, but in such a way that participants play a more active and creative role. Rather than carrying out research tasks designed by experts, they contribute to or question the design and agenda of the research, also in unexpected and unrequested ways. Yet, the distinction between citizen science and crowdsourcing remains a fluid one, also because both concepts continue to evolve (Horne, 2015).

Our project is developing a methodology to combine RRI and crowdsourcing as converging approaches to promote inclusive innovation, focussing on cohort research as an important research field. As indicated, although crowdsourcing may be seen as a form of citizen science, it has rather specific features which make it an interesting method for making cohort research more interactive and inclusive.

### 3 Epistemic inclusion

An important aspect of RRI is *epistemic inclusion*. RRI is not only about *social* inclusion (public participation, involving societal actors in the process of agenda setting) but also about “epistemic inclusion”: involving various forms of knowledge, perspectives, experiences and views from society, incorporating knowledge “out there”, outside academic quarters. The challenge then is, how to converge and reconcile various forms of (academic and non-academic) knowledge, or “knowledges” (Valkenburg et al., 2020). At the same time, the term “inclusion” still suggests a hierarchy of knowledge forms, where dominant knowledge forms (validated by established scientific methodologies) aim to become more open to outsiders’ views (which may be included as add-ons). Ideally, crowdsourcing recognises epistemic pluralism, aiming to integrate various knowledge forms, whether they are validated by scientific methodologies or for instance by practice. In the case of our project, although academic institutions take the initiative to reach out to crowds, the ambition is to create platforms and initiate a process where different knowledge forms collaborate and challenge one another.

Whereas in the past innovation progressed at the expense of other knowledge forms, even resulting in “epistemicide”, i.e. the active liquidation and elimination of other (e.g. traditional and indigenous) knowledge systems (Hall and Tandon, 2017), time has come to counteract this trend through participatory research, knowledge democracy and mutual learning. This does not mean *questioning* the importance of technoscientific expertise, but rather involving it in a public agora of dialogue and interaction. Mutual learning aims to bring together various groups of stakeholders (researchers, potential users, intermediaries, professionals, students, media, broader publics) to facilitate an interactive learning process through mutual exposure of views and experiences, expectations and concerns (Zwart et al., 2017). In terms of knowledge production, it aims to supersede the divide between researcher and research subject or respondent. In terms of communications, in contrast to more traditional (linear) forms of deliberation (such as lectures, panel discussions or question-and-answer sessions before a relatively large audience), innovative methods must be employed to encourage in-depth dialogues, taking us beyond traditional “experts vs. lay audience” forms of exchange, thereby allowing participants to mutually probe and question each other’s views. We are all experts to some extent (Collins, 2014). In other words, in society as a living laboratory, expertise has become ubiquitous. Besides a wealth of insights and knowledge, there are many knowledge deficits as well, notably in the sense that the future is open and indeterminate and it is difficult to predict how technologies will evolve and how the life-world will be affected.

## 4 Cohort research

We believe that cohort research is a research field which can benefit from the “participatory turn”, using crowdsourcing as a method. The objective of our project is to make cohort research more sensitive to societal expectations and concerns and to promote equal access to science, especially in the field of health and life sciences by engaging cohort participants, citizens and other groups of societal actors (i.e. policy makers, business/industry, non-governmental organisations, education community) in a more co-creative manner. Crowdsourcing may enrich cohort research by tapping into the collective intelligence of the community (questions, needs, concerns, insights, experiences etc.) and to create spaces for reflection. At the same time, it may increase citizens’ understanding of and trust in science, and perhaps counteract the decreasing preparedness of citizens to participate in medical examinations of cohort research. To achieve this, a participatory turn in cohort studies is crucial. Rather than seeing participants mere as respondents, as providers of data, they should become active partners in the research, adding questions, concerns and experiences, broadening the scope of cohort research, transcending the biomedical model and involving life-world knowledge. Crowdsourcing should help us to achieve this goal.

There are multiple dimensions of health. Besides the biomedical (third person) perspective (seeing participants as research subjects), there is a first-person perspective, focussing on health experiences, health culture and health behaviour in the concrete context of the lifeworld. Cohort studies as such already have the ambition to enter the real world of every-day practices and experiences. Crowdsourcing adds to this by allowing participants to play an active role and to broaden the scope, involving aspects of health culture and behaviour important to them, thereby enriching our understanding of key determinants of health and human flourishing, by allowing participants to speak and share experiences and concerns in their own voice and language.



## 5 Crowdsourcing

Having outlined the general profile of RRI and the trend towards inclusive research and mutual learning as a way to make research more responsible and responsive, the goal of our project is to use crowdsourcing as a concrete method to achieve this goal in the context of cohort research. 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). Applications of crowdsourcing have been grouped into various ways, e.g. into human computation, crowd competitions and peer collaboration (Hansson et al., 2019) or microtasking, information pooling, broadcast search, and open collaboration (Blohm et al., 2017). Based on a recent review of internal crowdsourcing approaches (Pohlisch, 2021), a systematization approach was proposed by (Wedel and Ulbrich, 2021), which we apply in JoinUs4Health. In conclusion, crowdsourcing is an evolving method, which provides opportunities to become more inclusive and interactive. It is precisely here, we argue, that crowdsourcing and RRI can mutually benefit from one another.

There is a long tradition of the opposite attitude, namely crowd phobia, going back to the work of Gustav le Bon, seeing crowds as impulsive, irrational, easily inflammable, vulnerable to manipulation (“hypnotisable”), indifferent to truth, and so on (le Bon, 1895). Crowdsourcing opts for an antithetical position, but based on a sophisticated (albeit evolving) methodology. Several proposed roles (e.g. “Reviewer: posting”, “Facilitator”, “Moderator”, “Mentor”) ensure that suggestions and contributions adhere to minimum quality standards avoiding clusters of like-minded individuals to create parallel worlds, – one of the risks involved in crowd-building via social media.

Crowdsourcing has already been applied as a concrete instrument for operationalising RRI in a recent paper based on an RRI project funded by the Research Council of Norway (Molla et al., 2018). However, to the authors’ knowledge, no other publication has specifically drawn the link between crowdsourcing and RRI, which is surprising given several points of intersection between these approaches. Other instances where crowdsourcing has been mentioned in relation to RRI was in the context of gathering research questions in the projects “Reden Sie Mit” and “Tell Us”<sup>2</sup> conducted by the Ludwig-Boltzmann-Association in Austria<sup>3</sup> and crowdsourcing being suggested as a methodology for co-creation on the RRI Tools website<sup>4</sup>.

Similar to RRI, for instance, crowdsourcing makes use of and aims to increase collective intelligence, which particularly enhances the understanding of complex challenges by combining different viewpoints (systems thinking). Crowdsourcing can also improve coordination and collaboration among stakeholders. Other shared potential benefits of RRI and crowdsourcing include mutual learning (Magnussen and Stensgaard, 2019, Magnoussen and Stensgaard, 2019), innovation (Milotay and Sgueo, 2020) and cross-fertilization (Gimpel et al., 2020).

Here we outline a methodological approach, which aligns crowdsourcing with general concepts of RRI. Features of this approach were first proposed to bridge the gap between science and public health (Schauer, 2018), but is in principle applicable to any other evolving research field. When specifically linking RRI and crowdsourcing, ideally all four strands of the QH should be involved, i.e. academic research, business, government and society.

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<sup>2</sup> <https://corona.lbg.ac.at/> and <https://tell-us.online/de>

<sup>3</sup> <https://www.youtube.com/watch?v=-IR1r6rjGiY&feature=youtu.be>

<sup>4</sup> <https://rri-tools.eu/how-to-stk-bi-how-to-boost-creativity-and-involve-people>

Traditionally, crowdsourcing includes four elements (Brabham, 2013):

- an individual or an organization has a task (questioner),
- a community addresses the task (crowd),
- a platform enables the task to be addressed and crowd members to interact,
- a benefit arises for both the questioner and the crowd.

## 6 Key Features

An overview of the core mechanism is shown in Figure 2.

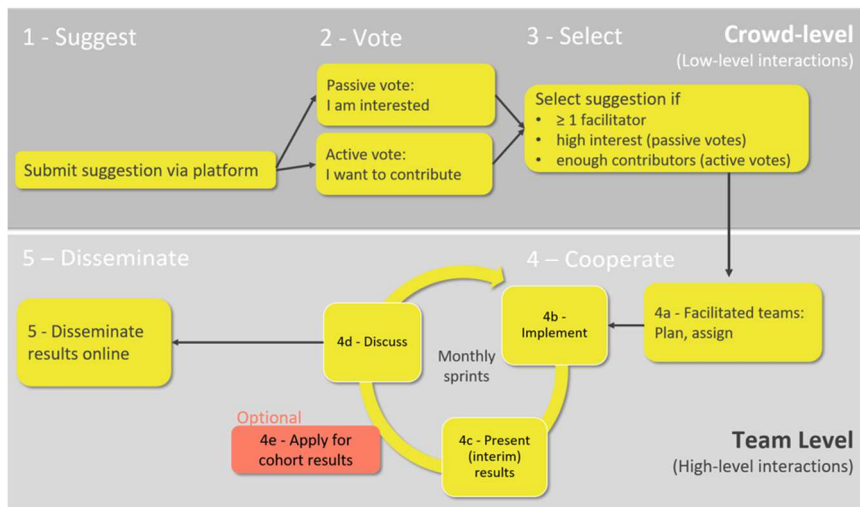


Figure 2. Core mechanism of JoinUs4Health with five core steps.

We postulate several key features of a crowdsourcing approach suitable to promote RRI and mutual learning.

### 6.1 Everyone can act as questioner or crowd member

A key adjustment to the traditional crowdsourcing approach is that any individual of the crowd regardless of the QH strand may either act as questioner (suggesting questions / tasks) or crowd member (vote; contribute time, knowledge or money). Questions may for example comprise proposed research questions to be investigated as well as questions relating to existing knowledge or real-life experiences. Tasks refer to specific actions, for which input is sought. Examples of tasks are 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).

### 6.2 Low-level interactions via an online platform

Submitted suggestions or tasks are screened by trained crowd members (“Reviewer: Postings”) and categorized in a standardized manner (filtering criteria) before being collated in a search database to facilitate ease of navigation, cluster similar suggestions together and ensure quality. Crowd members can screen suggestions via search and filtering functions, promote suggestions by submitting their support (vote) or comments (reviewed by trained crowd members before being made public) and express willingness to contribute time or money to help addressing a given question or task. Such activities (submissions, screening, voting, indicating willingness to contribute) are termed “low-level interactions” as at that stage no direct exchange takes place between crowd members (no forum dialogue). “Mentors” can provide relevant background materials (e.g. available research, further information), revise and summarize comments by crowd members.

### 6.3 Crowd members take over core functions

The subsequent processing of a question / task requires different roles of crowd members. As mentioned under Section 5.2, “Reviewers” screen postings prior to submission to the database based on standard criteria (e.g. precision, clarity) and (if required) ensure that adjustments (shortening of texts, standardization of terminology) did not alter the originally intended

meaning. “Mentors” (optional) may promote topics, which have raised considerable interest amongst crowd members, but have not yet attracted sufficient voluntary contributions, diversity or expertise.

#### **6.4 Democratic process with option of crowdfunding**

Since it is not possible to address all proposed questions / tasks, a transparent process needs to be applied to select questions/tasks via low-level interactions described in Section 5.2. For instance, crowd support (votes), the number, skills and diversity of volunteering individuals and the availability of a “Facilitator” may be taken into account. Voluntary input may be enhanced by paid input via the option of crowdfunding.

#### **6.5 High-level interactions via teams**

Once a question / task has been selected to be addressed, teams are formed. At this stage, high-level interactions take place as team members may interact directly. A trained “Facilitator” is responsible for coordinating teams and ensuring standard reporting of plans, progress and outputs. Teams may apply various approaches.

For instance, at an exploratory stage, focus group discussions or Delphi questionnaire methodology can be used to explore key points related to the question of interest and develop a research proposal specifying tasks and roles. Tasks are subsequently addressed via direct exchanges (virtual meetings, discussions with experts, review, ...) ideally breaking down larger tasks into smaller sprints so to offer a circumscribed time of commitment. Such high-level interactions match the crowdsourcing types “Broadcast Search” and “Open Collaboration” (Blohm et al., 2017). Teams will frequently require information to be reviewed. Tasks like this can be outsourced to the crowd if the team itself does not include sufficient volunteers or expertise (resembles “mikrotasking” Blohm et al. (2017)).

#### **6.6 Science-based best practice approach**

The framework for this concept needs to be transparent and should ideally be based on guidelines or standards adjusted to the crowdsourcing initiative, which also form the basis for training. Regular documentation of high-level interactions on the online platform allows crowd members and other teams to view the plan, progress and outputs of active teams. The guidelines need to be flexible enough to provide freedom in implementation, but sufficiently standardized to allow transparent documentation to be stored in the search database and protection at various levels (data, privacy, resolution of conflict).

#### **6.7 Maximum automation**

“Hand-holding” is progressively reduced by training crowd members to apply standards defined for this crowdsourcing initiative. Hence, any crowd member can undergo online training and certification covering different levels (beginner, intermediate, advanced) to take on different roles. Therefore, the crowd increasingly takes over core roles to maintain basic functionality of the crowdsourcing system. If additional expertise is required, which cannot be sourced via the crowdsourcing approach, external experts and further crowd members are sought via (Network) Promotors.

#### **6.8 Inclusiveness**

The crowd is a highly heterogeneous group of individuals and sub-groups. The interest in and perceived value of such a crowd-driven approach as well as opportunities and barriers vary between individuals and groups. Therefore, it is crucial to provide various options of engagement depending on an individual’s time, interest, interactivity, background and preparedness to contribute. At the stage of low-level interactions, individuals are rather passive

by proposing, voting, indicating support and reading. High-level interactions in the form of moderated teams or taking on tasks individually to support active teams should ideally involve various types of contributions suitable for different personality types. Endorsements of skills and facilitators' reports could be used to describe individual strengths and weaknesses, which could be specifically promoted or targeted.

## **6.9 Voluntary contributions coupled with recognition and incentives**

The proposed crowdsourcing approach is primarily based on voluntary contributions, thus generally not providing monetary incentives. Individual benefits may arise from other forms of incentives, such as recognition, gamification features and non-monetary rewards. In some cases, crowdfunding may generate opportunities for paid contributions. Given the voluntary nature of the concept and the need to value each individual's time commitment the system should strive toward maximizing return on "voluntary contributions" to make efficient use of voluntary inputs. Ethical aspects of such a crowdsourcing approach need to be explored in detail, which suits RRI with ethics as one of its four key dimensions.

Benefits of this approach arise primarily for the overall system due to the creation of innovative ideas and diverse knowledge and for society due to the translation of research into lay-person language. This system-level benefit becomes more tangible for individuals if a process is in place to systematically communicate the most viable outputs to the different QH strands. For instance, online conferences or science/policy newsletters would be possible approaches to allow those teams who were ranked most successful by crowd members to present their outputs and ideas directly to scientists and policy makers. Key outputs could be translated into a format, which can be easy to digested and applied by citizens.

## 7 Caveats

Crowdsourcing is neither about popularising research, nor about communicating about research in a linear fashion, nor about “socialising” citizens in scientific research and introducing them to the process of science insofar as this science (e.g. cohort studies) is still rooted in the traditional linear paradigm. For crowdsourcing to become co-creative, crowdsourcing projects should not be conducted using a platform which is still anchored in “the scientific method” as we currently know it, for example by analysing data from the cohort or conducting literature reviews, listening to expert opinion etc. Rather, crowdsourcing should enable citizen scientists to conduct transdisciplinary research that integrates different types of knowledge through co-creation with actors from outside the platform, ensuring the inclusion of voices that would otherwise be excluded in research facilitated by the crowdsourcing platform. Thus, by developing crowdsourcing as a methodology for RRI implementation, we hope to foster a new generation of citizen scientists that, have a broader understanding of scientific research that is anchored on complexity and transdisciplinarity.

Additionally, through training and encouraging citizen scientists to conduct transdisciplinary and co-creative research, we aim to promote the involvement of professional scientists with RRI. Researchers are trained to be hyper-specialists and prioritise scientific knowledge over other types of knowledge. For scientists to engage in co-creative knowledge production, they must unlearn that knowledge hierarchy and abandon the hyper-specialist and reductionist view on the topic investigated. In crowdsourcing, this process can be facilitated by collaborating with citizen scientists who are trained in such co-creative methods, since citizen scientists are quicker to adopt new ways of thinking about research given that they do not require such extensive unlearning. Contrastingly, if crowdsourcing were implemented through promoting traditional “scientific” practices among citizen scientists, citizen scientists might expect that professional researchers fall back into the expert role, thus perpetuating the old paradigm within the crowdsourcing platform.

Putting RRI in practice is not an easy objective to achieve. For instance, stakeholder engagement is quite demanding, and RRI activities should not be a one-time event, but rather directed at establishing enduring interactive relationships. This can only be achieved if we reconsider the way in which research is organised, assessed and rewarded, paying more attention to societal interaction compared to h-indices and publications in high-impact journals. RRI / QH should not be cosmetic activities, but rather arise from a genuine concern to strengthen societal embedding of research.

Finally, as indicated, this document does not provide a ready-made validated methodology, but stipulates important principles and guidelines. Although terms like “method” and “methodology” are often identified with rigid research protocols, notably of the experimental type, the literal (etymological) meaning of “method” rather suggests that it is something that is developed *along the way* (μετ’ + ὁδός in Greek, where ὁδός means “road”). From an etymological point of view (Zwart 2021), method means openness, a willingness to share experiences and consider the path we are exploring together collaboratively. Therefore, crowdsourcing is an evolving method, which will be fine-tuned along the way, so that methodology development is an inherent part of our collaborative effort.

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