Time4CS webinar: “Ethical aspects of Citizen Science: good practices and institutional interventions”
16.05.2023

Methodology and case study

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Outline

1. Project and cohort institutions
2. Concept and platform
3. Example topic: Digital event series for pubic health representatives
4. Status and outlook
5. Questions

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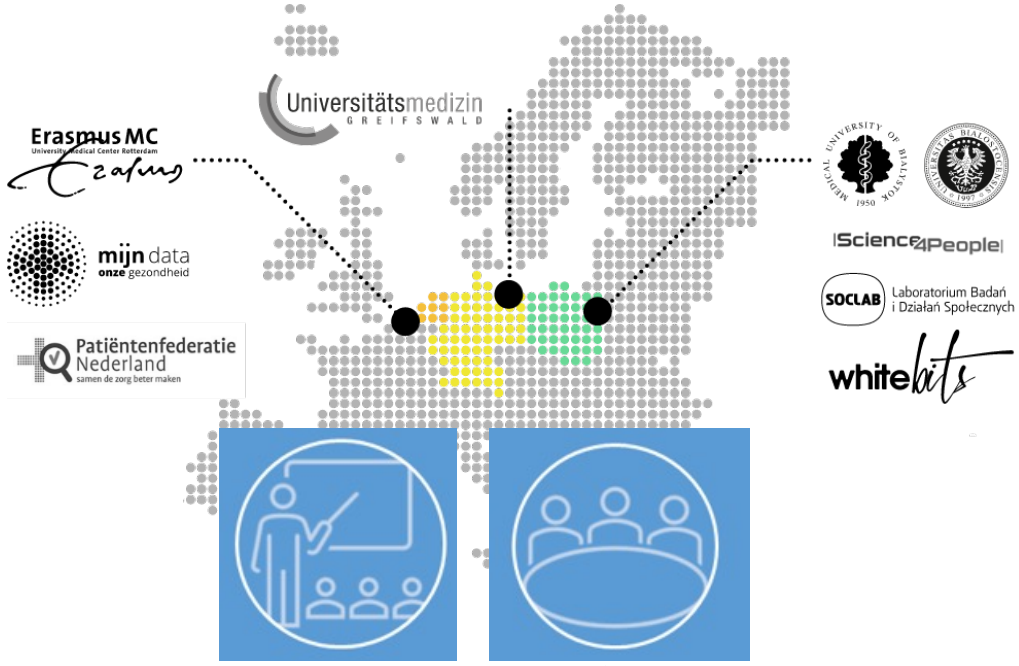
1. Project and cohort institutions

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The project and our goals

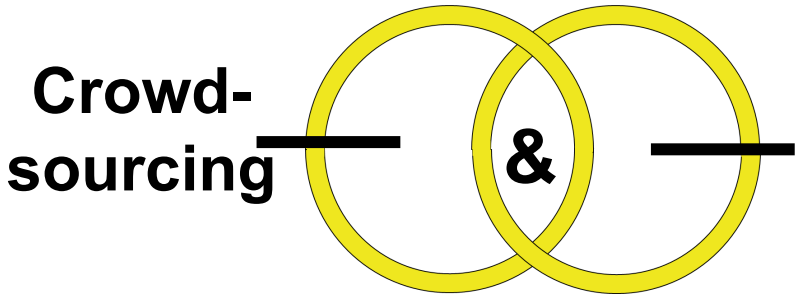
Title: *Join Us to Optimize Health in Cohort Research*

- Project period: 01/21 – 12/23
- 11 partners from three countries



Move from deficit to dialogue framework

Overall aim: *Combine*



… to promote

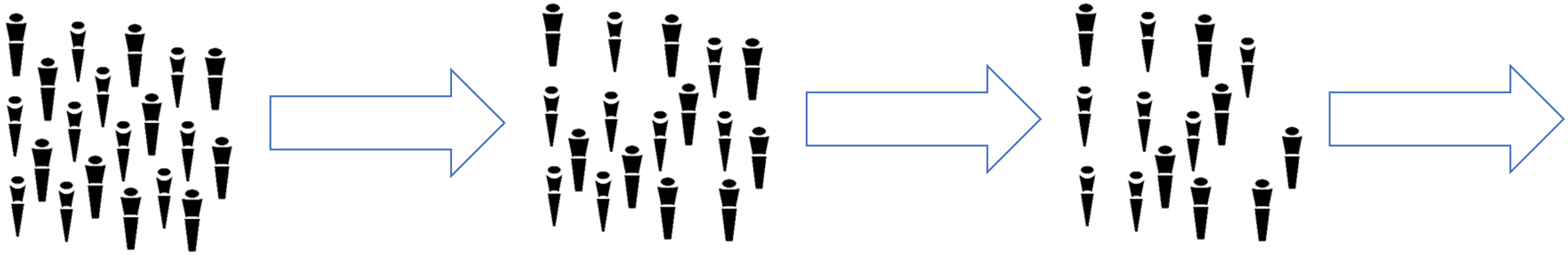
- inclusive innovation and
- citizen engagement

in cohort research

Cohort research

Randomly selected

Same individuals are followed over time



Baseline examination

1st follow-up

2nd follow-up

…

Cohorts participating in JoinUs4Health: Examinations in ~ 5 year-intervals

Overview of available cohort data

Cohort project	Country	Cohort	Start	n	Response (%)
Study of Health in Pomerania (SHIP)	Germany	SHIP	1997	4,308	68.8
		TREND	2003	4,420	50.1
		NEXT	2021	[4,400]	na [a]
Bialystok Polish Longitudinal University Study (PLUS)	Poland	PLUS	2018	637	45.4 [b]
Rotterdam Study (RS)	Netherlands	RS-I	1989	7,983	78.1
		RS-II	1999	3,011	67.3
		RS-III	2006	3,932	64.9
		RS-IV	2016	3,368	46.0
Total				27,659	

[a] Ongoing; started in 2021 (target: 4400 participants until 2026)

[b] Ongoing: started in 2019

Different focus of the cohorts

Education
- Minor
- RRI to be taught as part of Master programme

Engagement public health authorities
- Digital event series

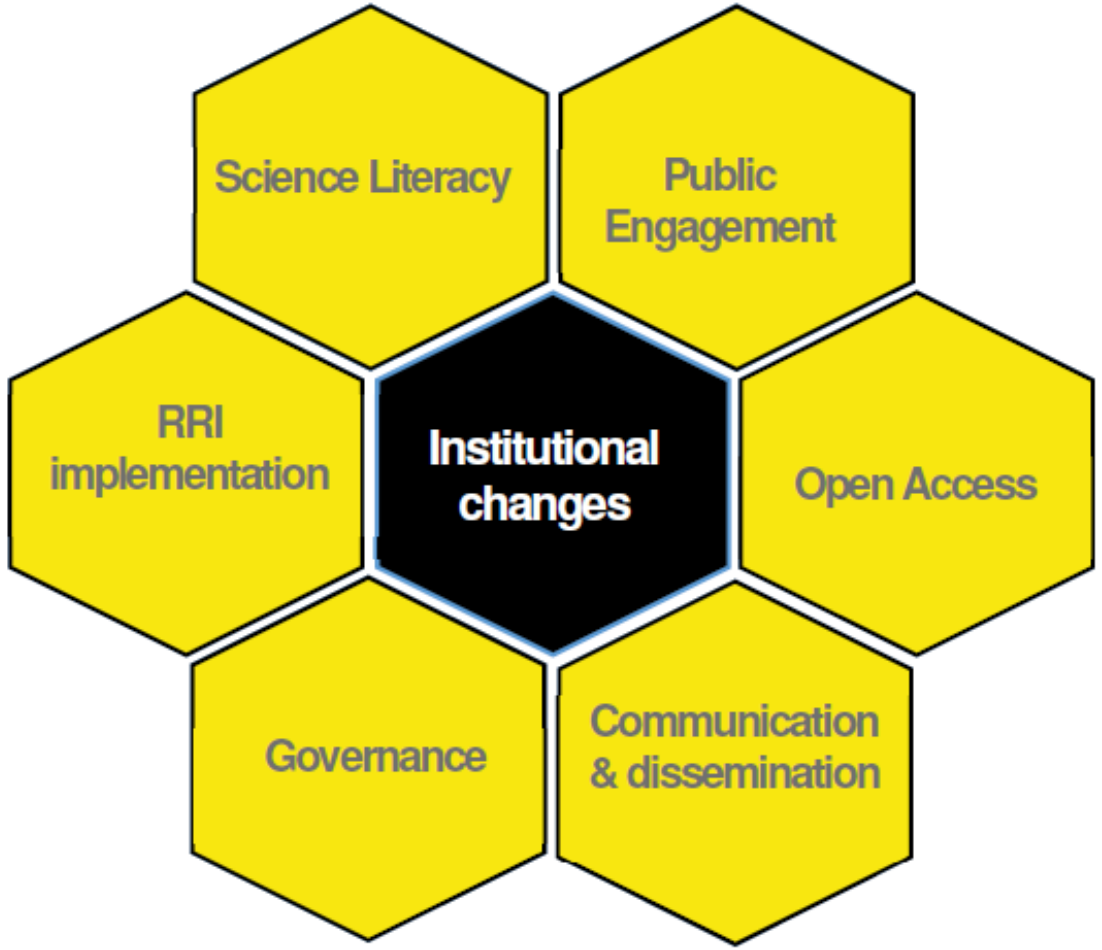
Offline activities
- Quadruple helix workshop
- NGO workshop
- Hackathon
- Health festival
- Youth conference on mental health

Six institutional changes

See deliverables

- 4.1: Report on the concept of RRI institutionalization under the JoinUs4Health project
- 4.2: Report on the implementation of institutional changes

https://joinus4health.eu/about/for-researchers/



2. Concept and platform

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Definitions in brief

Crowdsourcing

- NOT crowdfunding
- Voluntary contributions of time, ideas, etc.!

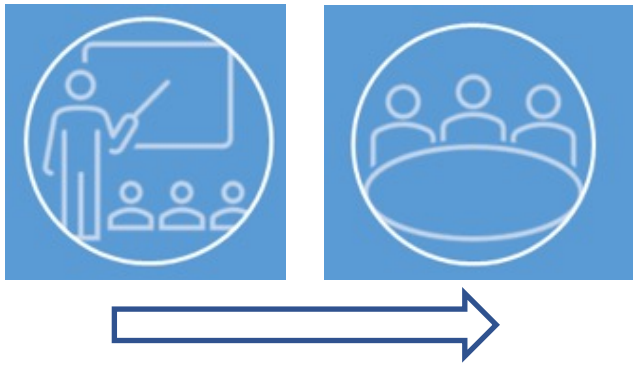
Responsible Research and Innovation

- anticipation of the future societies that we wish for,
- reflexivity by researchers and innovators on the effects of their work,
- inclusion of relevant stakeholders, and
- responsiveness to the needs and ambitions of society

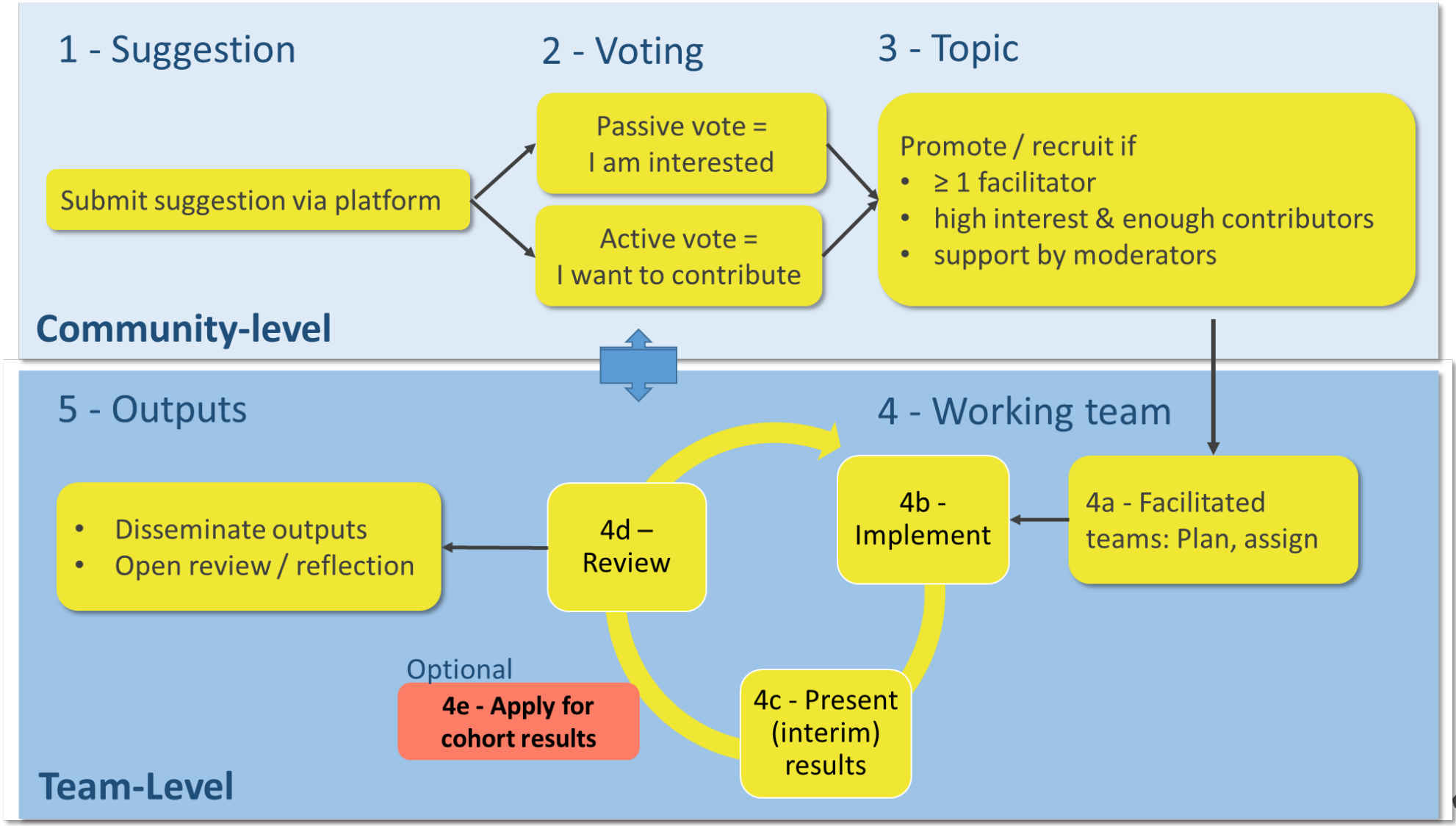
Further information: https://rri-tools.eu/

Also

- move from deficit to dialogue framework
- flattening of hierarchies
- co-creation



Schematic overview of concept



Responsible Crowdsourcing

Crowdsourcing as a form of citizen science

Towards involving citizens in the entire research process, as more than data sources or data collectors

Why crowdsourcing?

- Interaction with large amounts of people

- Asynchronous and displaced interactions

Why is responsible crowdsourcing different?

Responsible crowdsourcing combines consultive mechanisms with intense co-creation methods

Proposed roles

Facilitator

- flexible role (tied to given topic, task or team)
- anyone can act as facilitator

Tasks

- coordinates contributors incl. planning and summary of outputs
- oversees implementation of agreed plan
- monitors adherence to code of conduct
- in contact with the moderator

Moderator

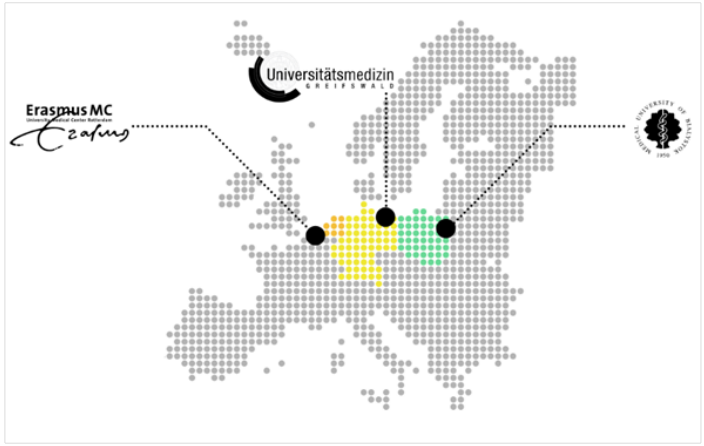
Tasks

- high-level input
- provides mentoring role on RRI-related aspects
- 1st contact in case of questions, complaints
- reviews plan and (interim) outputs

Strategic oversight: Advisory boards

3 Citizen Science Boards
(1 per country)

- meet monthly
- tasks: review / decision-making in relation to platform contents and community requests

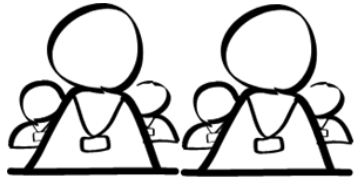


3 Monitoring and Evaluation Groups (1 per country)

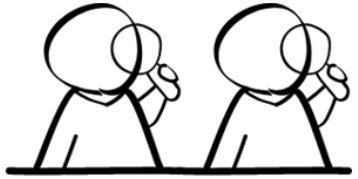
- meet quarterly
- tasks: monitoring and evaluation, reflection, strategic decision-making



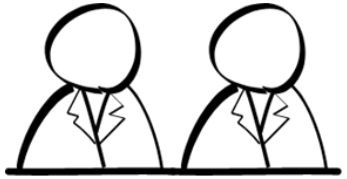
Education community



Citizens & Civil Society Organizations



Research community



Business & Industry



Policy makers

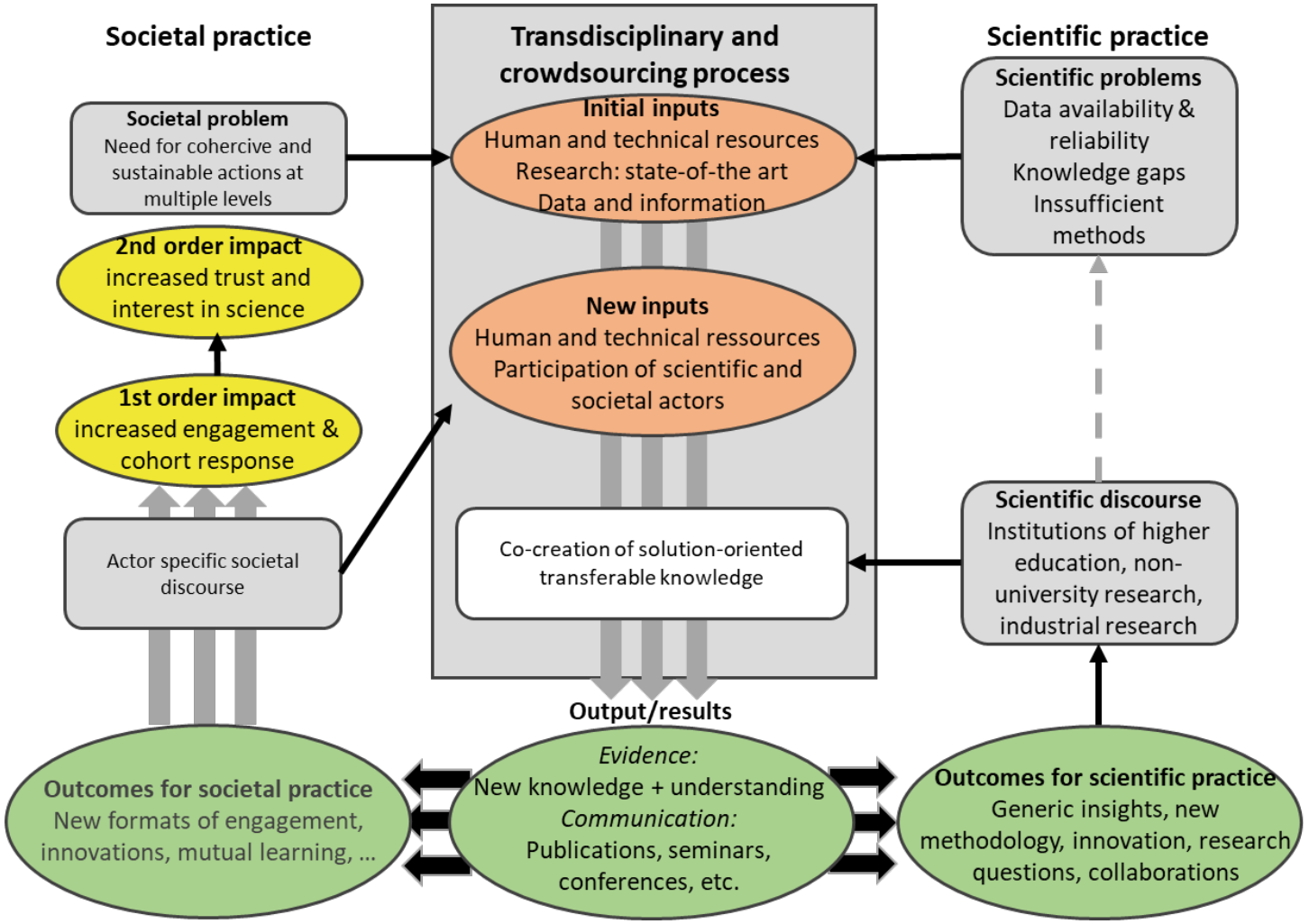
Ten members (2 x 5 people per group)

- Citizen Science Board and
- Monitoring and Evaluation Group

In total: 2 advisory boards in 3 countries with 10 board members each

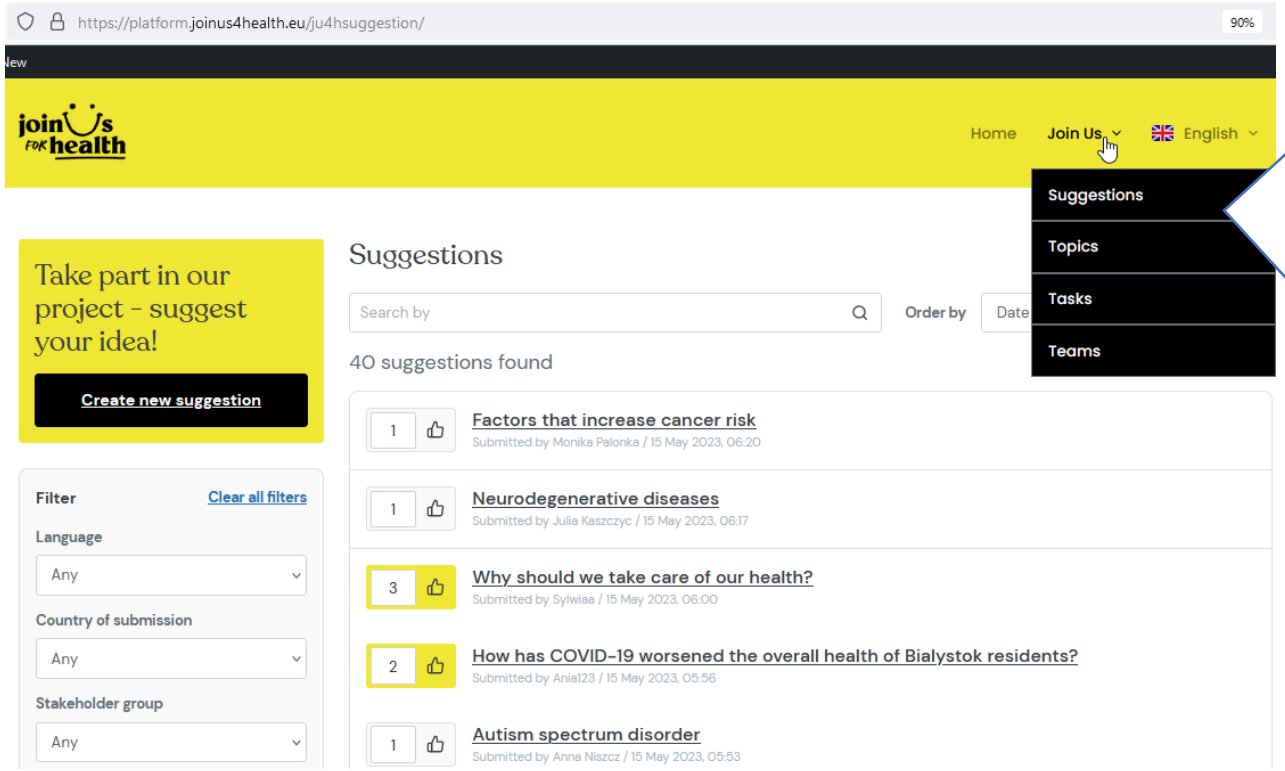
→ 60 advisory board members

Change pathway

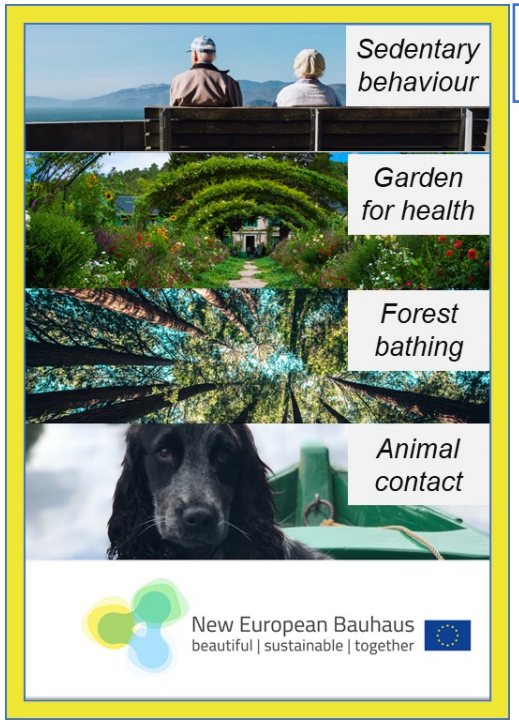


Adapted from Rüegg, Häsler, et al. (2018): A handbook for the evaluation of One Health

Platform



- ‘Suggestions’ and comments reviewed prior to release
- ‘Topics’, ‘Tasks’ and ‘Teams’ require facilitator and moderator



First topics

Link to platform:
https://platform.joinus4health.eu/

3. Example topic: Digital event series for pubic health representatives

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Concept originated in 2017 targeting the interface science and public health

Opinion Volume 7 Issue 4

Crowd sourcing to bridge the gap between science and public health

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Received: July 17, 2017 | **Published:** July 19, 2018

Citation: Schauer B. Crowd sourcing to bridge the gap between science and public health. *MOJ Public Health*. 2018;7(4):189–190. DOI: 10.15406/mojph.2018.07.00226

Download PDF

Overview

- Target group: Representatives of German Public Health authorities
- Type of activity:
  - four-part digital event series
  - organized by the Academy of Public Health
  - linkage with JoinUs4Health platform between events 2 and 3
- Academy for Public Health
  - founded in 1971
  - financed by 13 out of 16 federal states in Germany
  - responsible for apprenticeships, trainings and further education of all public health service employees
  - annually over 8000 participants
  - one of the 11 JoinUs4Heatlh partners

Making cohort research useful for the public health service

Apply crowdsourcing (internal, Joinus4Health, public health sector)

Event 1
27/06/23

- introduction
- explore cohort data catalogues
- discuss applications
- collate suggestions

Event 2
29/06/23

- discuss suggestions
- select ≥2 scenarios
- define work plan
- apply for cohort results

Events 3 and 4
Late Nov / early Dec

For each scenario
- report of activities and level of engagement
- present results
- discuss

Evaluate outputs from in terms of potential transfer into the practice of public health

1 - Suggest

2 - Vote

3 - Promote / mobilize

4a – Collaborate

4e - Apply for cohort results

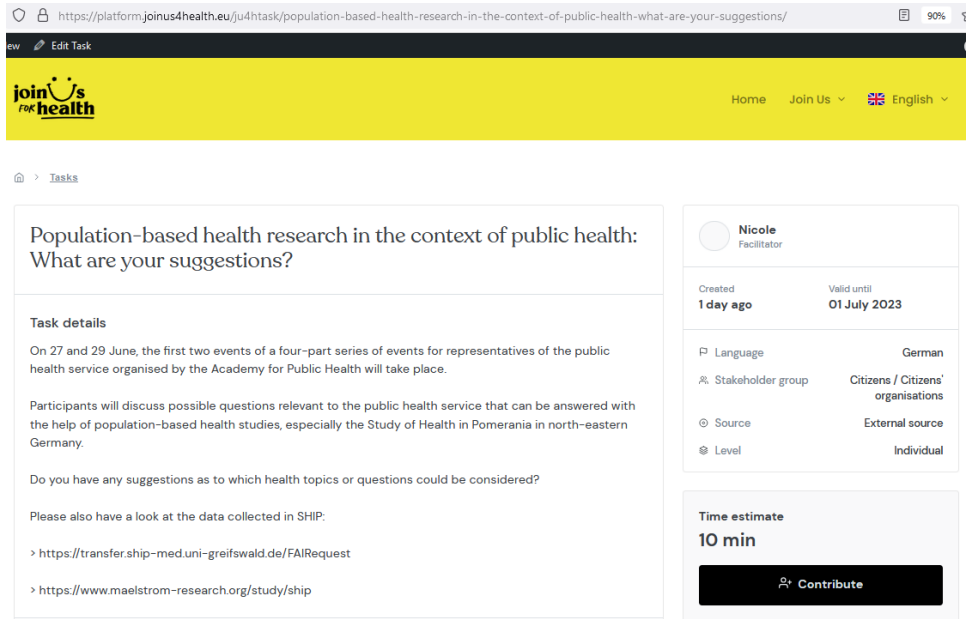
4b – Revise and evaluate

Overview

TOPIC



TASK



4. Status and outlook

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Initial assumptions

- provision of online platform & promotion of platform and concept would
  - lead to numerous suggestions,
- over time, we would mobilise an increasing number of volunteers to carry out follow-up activities:
    - Teams and
    - Tasks
- crowdsourcing concept could be increasingly implemented and tested in practice
- at the end of the project period,
  - volunteering contributors would have gained experience with the concept and requirements
  - some of them would increasingly take over moderator and JoinUs4Health-associated tasks
- cohorts provide additional input or input upon request (e.g. result preparation)

Actual experiences

- few activities emerged to date (platform release in 04/22) - interest is rising
- considerable investment of time was necessary to mobilise networks and individuals
- online and offline outreach activities were combined in attempt to build an active online community

Challenges faced in citizen science projects

- many Citizen Science projects face challenges in
  - attracting enough contributors,
  - coordinating project work,
  - ensuring the quality of processes and outputs, and
  - reconciling scientific as well as non-scientific project goals
- many professional scientists remain sceptical about involving non-professionals in research

Crowds, citizens, and science: a multi-dimensional framework and agenda for future research

Chiara Franzoni, Marion Poetz & Henry Sauermann

To cite this article: Chiara Franzoni, Marion Poetz & Henry Sauermann (2022) Crowds, citizens, and science: a multi-dimensional framework and agenda for future research, Industry and Innovation, 29:2, 251-284, DOI: 10.1080/13662716.2021.1976627

Outlook

- platform and website will be run for at least 3 years after the end of the project (01/2024-12/2026)
- all three cohort institutions are willing to continue implementing institutional changes
  - regional variations exist
  - priority given to activities within the study regions
- but
  - no paid position anymore
  - reliance on volunteering input
  - ongoing support by leadership level required

5. Questions

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What to do with the ethical concerns that could arise within a given topic?

Advisory board



Platform community

JoinUs4Health-related

Scientific Steering Committee of the cohort institution

Ethics Committee

At cohort institutions

How to manage the relationship between institutional and non-institutional partners?

Cohort representatives

- advisory board: to be part of it?
- role as part of processes: to
  - initiate suggestions / topics?
  - use platforms to communicate / translate findings (e.g. DDR Psych)?
- role on platform: to act as moderator?



Does the same apply to all institutional actors?

Avoid power imbalances and aim to ensure responsible crowdsourcing:

- need to fulfil moderator role to ensure the “RRI umbrella”!

Other challenges faced

- three partners: Severe staff shortages
  - problems when recruiting staff due to various reasons
  - partly prolonged absences due to sick leave
  - Problems in coordinating work / meeting timelines
- lack of time to co-create the platform
- differences in views amongst partners (e.g. role of institutional actors)


https://joinus4health.eu/about/for-researchers/

M6.2 Concept of communication and dissemination strategy both in online and offline environment [Jun. 2021 / Mar. 2022]

M6.3 Concept of evaluation activities concerning communication and dissemination strategy execution [Oct. 2021 / Nov. 2021]

M6.4 Concept of standard operating procedures for activities in schools (competition, internet platform usage, on-line courses, classes) [May 2022 / -]

M6.5 Peer-reviewed publication on engagement, communication and dissemination [Nov. 2023 / -]

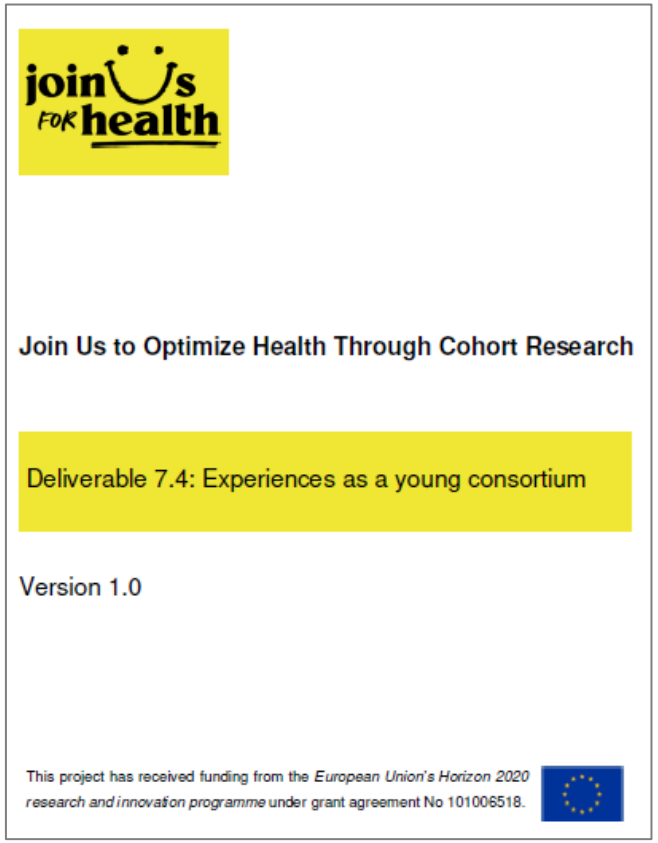
Work Package 7 – Coordination, Monitoring and Evaluation

D7.1 Monitoring and evaluation (M&E) framework [Aug. 2021 / May 2022] Download pdf↓

D7.2 Data management plan [Oct. 2021 / Apr. 2022]

D7.3 Final M&E report [Oct. 2023 / -]

D7.4 (defined during mid-term review) Experiences as consortium [Oct. 2023 / Apr 2023] Download pdf↓


Join Us to Optimize Health Through Cohort Research

Deliverable 7.4: Experiences as a young consortium

Version 1.0

This project has received funding from the *European Union's Horizon 2020 research and innovation programme* under grant agreement No 101006518.

Subscribe to our newsletter!



https://joinus4health.eu/
https://platform.joinus4health.eu/

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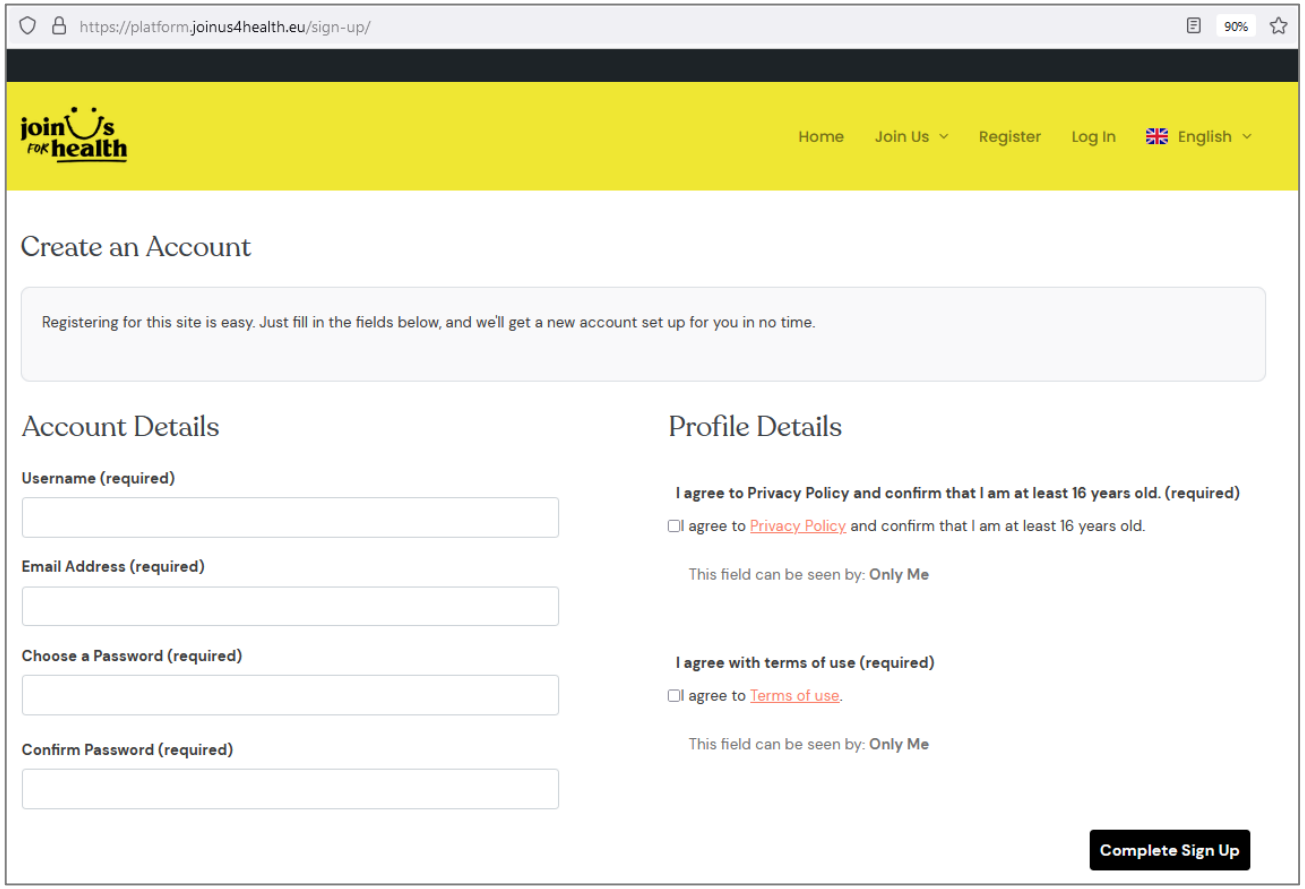
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Data protection

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Data protection

- Hosting provider for website and platform
  - inside Europe
  - bound to European law and us by contracts
- Platform: Upon registration, the user specifies
  - user name (fictional or non-fictional)
  - email address
  - password



No tracking of user-related information

- privacy through data minimization (GDPR Art. 47)
- no third party tool to track user related information: locally running analysis tools:
  - Webalizer
  - Matomo (implementation in progress)
- only technically needed session cookies
- IP addresses are stored for 14 days

Privacy policy and register of processing activities

Privacy policy:

- describes
  - how user information is collected,
  - for what purpose it is used and
  - what rights the user has over it
- accessible in German and English: via link in footer

Register of Processing Activities (Verzeichnis von Verarbeitungstätigkeiten; VVT)

- Clear specifications which persons and processes can access which type of data

Databases

- two separate databases:
  - platform contents and
  - personal user data such as profile data
- the separation of content- and user-data adds a layer of security to protect the most sensitive information from unauthorised access