GIMM CARE

Best Practices in Citizen Science in the Biomedical and Health Sciences

Living Document V3.0

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Contents

Introduction and methodology

This document serves both as an introduction to *Citizen Science* in the health sciences, and, more importantly, as **practical guide and a repository of best practices** to guide GIMM CARE and GIMM Discovery researchers in including citizen science in their research. As a living document it will be updated regularly, to reflect new scholarship in this field and experiences gained by GIMM researchers in developing their own citizen science practices.

While citizen science has been well developed in scientific fields such as astronomy, biology, the environmental sciences, including in Portugal (Luís 2022) its application in the health sciences remains comparatively limited. Out of the 349 projects available at the EU Citizen science platform,[1] only 49 have health and medicine among their topics. Projects with a particular focus on biomedical sciences are even fewer. In the Portuguese platform of citizen science there are 7 projects that are included in the domain Health and Medicine (several of which have a stronger environmental component).[2]

Nevertheless, there is a long tradition of citizen involvement in biomedical research, from less intensive degrees of engagement, such as sample donation or clinical trials, to the more intensive engagement of advocacy work by patient organisations and “treatment activism”.

It should be noted that the health sciences are a widely diverse field, with a multitude of research topics, methodologies and procedures. Not all research in the health sciences is suitable for including citizen science. Participatory approaches to research, while commendable and useful in many cases, are not mandatory or necessarily appropriate in every context. It falls on researchers (and support staff) to decide if and when and how to carry out citizen science within their research projects.

The document is based on a **literature review** of academic publications regarding citizen science in the health sciences and a **set of interviews with practitioners of citizen science in Portugal** and at **the Vall D’Hebron Research Institute (VHIR) in Barcelona**. We are profoundly grateful to the researches and science officers who shared their experiences with us: Sara Mas from Vall D’Hebron Research Institute (VHIR), Maria João Leão from the Instituto de Tecnologia Química e Biológica António Xavier (ITQB NOVA) and Programa Ciência + Cidadã, Isabel Gordo, Karina Xavier and Patrícia Morais from the Gulbenkian Institute for Molecular Medicine (GIMM), Ana Rita Álvaro from the Center for Neuroscience and Cell Biology at the University of Coimbra (CNC), Diana Sousa and Francisco Rocha from Sociedade Portuguesa de Inovação (SPI). The second version of this document benefited from the revision by Cristina Luís, head of the Portuguese Network of Citizen Science, and additional inputs collected at the Encontro Nacional de Ciência Cidadã (Oeiras, November 2025)

Framing citizen science in the health sciences

Science performed by amateurs is an ancient practice, although we can only talk of citizen science after the professionalization of science. It has gained renewed meaning and relevance in recent years within the open science movement, in particular as part of the open engagement of societal actors (Figure 1). It is also associated with the rise of Responsible Research and Innovation sponsored by the European Commission in its Framework Programmes since 2010 (EC 2013).

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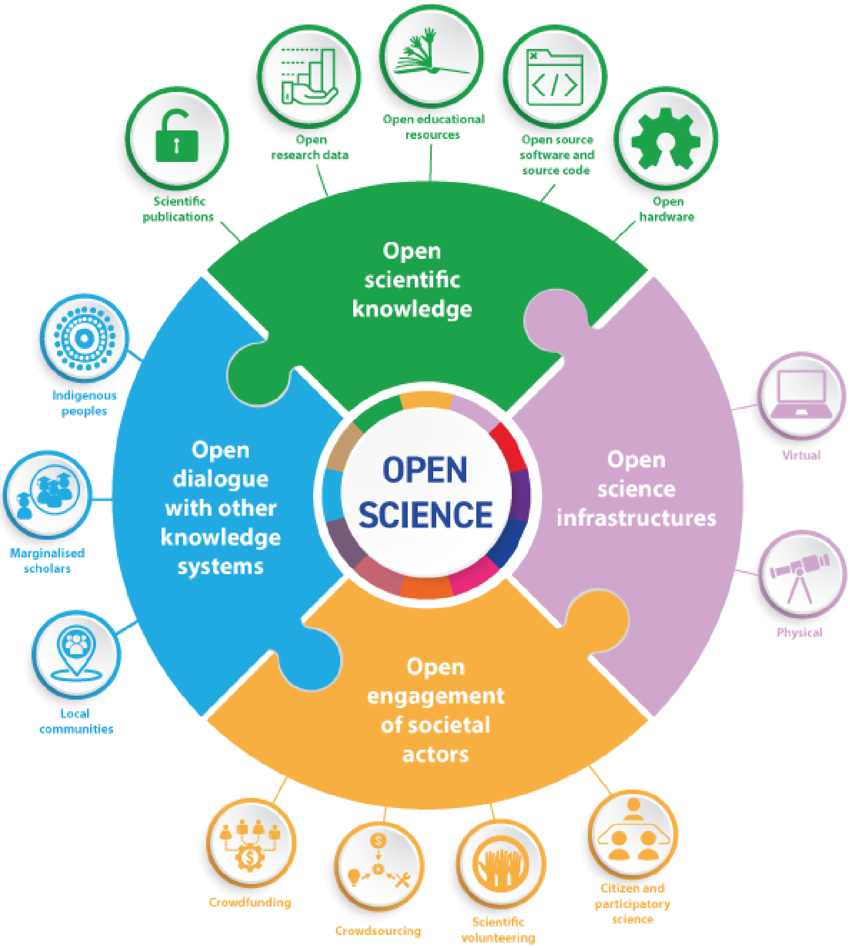
[1] https://eu-citizen.science/

[2] https://cienciacidada.pt/ Accessed on 20th July 2025

Figure 1. Pillars of Open Science.



Source: UNESCO (2022).

Definitions

There are multiple definitions of citizen science in the literature, but most are too generic to be of much practical use to discern what counts as citizen science (Box 1).

Box 1. Definitions of citizen science.

Citizen Science refers to the general public engagement in scientific research activities when citizens actively contribute to science either with their intellectual effort or surrounding knowledge or with their tools and resources. (Socientize, White paper on Citizen Science, 2015)

Citizen science' is the participation of non-professionals in procuring funding, collecting or generating data, analyzing, interpreting, and applying results, or evaluating and disseminating scientific research. (Fiske et al. 2019)

As a result, the European Citizen Science Association has opted to devise a Decalogue of citizen sciences principles to guide practitioners into developing projects that meet a set of criteria to be considered citizen science (Box 2).

Box 2. Ten principles of citizen science.

1. Citizen science projects actively involve citizens in scientific endeavour that generates new knowledge or understanding. Citizens may act as contributors, collaborators, or as project leader and have a meaningful role in the project.

2. Citizen science projects have a genuine science outcome. For example, answering a research question or informing conservation action, management decisions or environmental policy.

3. Both the professional scientists and the citizen scientists benefit from taking part. Benefits may include the publication of research outputs, learning opportunities, personal enjoyment, social benefits, satisfaction through contributing to scientific evidence e.g. to address local, national and international issues, and through that, the potential to influence policy.

4. Citizen scientists may, if they wish, participate in multiple stages of the scientific process. This may include developing the research question, designing the method, gathering and analysing data, and communicating the results.

5. Citizen scientists receive feedback from the project. For example, how their data are being used and what the research, policy or societal outcomes are.

6. Citizen science is considered a research approach like any other, with limitations and biases that should be considered and controlled for. However unlike traditional research approaches, citizen science provides opportunity for greater public engagement and democratisation of science.

7. Citizen science project data and meta-data are made publicly available and where possible, results are published in an open access format. Data sharing may occur during or after the project, unless there are security or privacy concerns that prevent this.

8. Citizen scientists are acknowledged in project results and publications.

9. Citizen science programmes are evaluated for their scientific output, data quality, participant experience and wider societal or policy impact.

10. The leaders of citizen science projects take into consideration legal and ethical issues surrounding copyright, intellectual property, data sharing agreements, confidentiality, attribution, and the environmental impact of any activities

ECSA (European Citizen Science Association). 2015. Ten Principles of Citizen Science. Berlin. http://doi.org/10.17605/OSF.IO/XPR2N

In the health sciences, there is an array of participatory activities involving patients or members of the public that can be considered citizen science or citizen science adjacent (see Box 3). While in some cases is just a matter of labels (whose popularity changes over time), in other cases these activities have distinctive characteristics.

For the purposes of this document, we will use the term citizen science throughout, although some of the recommendations may also be applicable to other forms of public participation, involvement or engagement.

Box 3. Participatory activities in health sciences research

Patient Engagement in Research “patient engagement in research refers to a spectrum of research that is co-produced with patients and other members of the public (including caregivers, family members, patient representatives and/or advocates) through a wide range of activities in which patients have varying degrees of influence on study decision-making” (Chudyk et al., 2024, p. 2)	**Patient and Public Involvement in Research** “research being carried out ’with’ or ’by’ members of the public rather than ’to,’ ’about’ or ’for’ them (…) is implemented in practice by having discussions with patients as partners in various aspects of research (ideally all). Patients are often involved in surveys, interviews or focus groups to provide their views on the research topic, research question, methods and resources available.” (Arumugam ey al. 2022, 2)
Participatory Health Research a research approach rather than a research method, in which participation is the defining principle throughout the research process. The primary underlying assumption is that participation on the part of those whose lives or work is the subject of the study fundamentally affects all aspects of the research. The engagement of these people in the study is an end in itself and is the hallmark of PHR, recognizing the value of each person’s contribution to the co-creation of knowledge in a process that is not only practical, but also collaborative and empowering. (Wright et al. 2019)	**Community-based Participatory Research** an approach in which scientists work closely with the local community in developing and implementing research likely to be of concern to members of the community. Citizens provide scientists with advice concerning the design of research projects, potentially including the research goals, design of questionnaires and survey instruments, subject recruitment, informed consent, and data interpretation and dissemination (Resnik et al., 2015)
Health Data Donation Participants create a federated dataset by submitting their own personal health data to a shared archive or repository. In some cases, the data may have been collected by the participants themselves. The data can be generated from digital technologies such as wearable devices, traces of online activity such as social media posts, or a patient’s medical tests or electronic health records. The key point is that the dataset is created collaboratively by the people who are represented within it. (Bietz et al. 2019)	**Popular Epidemiology** “it as a form of citizen science and a type of social movement. As a citizen science, popular epidemiology is a lay way of knowing that is based in part on an appropriation of expert knowledge by non-experts. As a social movement, popular epidemiology is a mobilization of citizens around the goal of identifying and ameliorating environmental stressors and local illness patterns.” (Brown 1997)
Co-creation/co-design/co-production “**Co-creation** refers to the collaborative approach of creative problem solving between diverse stakeholders at all project stages. It emphasises diverse stakeholders at all parts of an initiative process, beginning with determining and defining the problem through to the final stages of a project. The plan of collaboration is jointly set by co-initiating	**Living labs** “real-life experimental environment where both users and producers co-create innovative solutions through Public-Private-People Partnerships, fostering user-driven open innovation (…) an innovative approach to developing specific health problem solutions for aging populations and chronic diseases” (Kim et al. 2019).

stakeholders who call for collective action (...) **Co-design** describes active collaboration between stakeholders in designing solutions to a prespecified problem. It promotes citizen participation to formulate or improve specific concerns (i.e. service or product improvement, better prevention activities, more resources, better trained health promotion staff and, evidence informed initiatives) (...) **Co-production** engages stakeholders in the implementation of a previously agreed solution (strategy) to a previously agreed problem and focuses on how to allocate resources and assets within these constraints, to achieve better outcomes" (Vargas et al. 2022, 2).	

Citizen science projects in biomedicine can take many forms, including crowdfunding, data or specimen collection, self-tracking, social network and sharing platforms, gaming, or biohacking.

Why do citizen science in the health sciences?

The literature of this field presents several justifications for doing citizen science projects in the health sciences, many corroborated by interviews we conducted with practitioners. These justifications can be aggregated in five major factors: a) citizen science helps improve research processes, b) it improves the relations with patients and other end users, c) it can enhance the impact of research, d) it can bring economic benefits, and e) it can also benefit the researchers' careers (Table 1).

Table 1. Benefits of citizen science in the health sciences.

Improve research processes	• Acquire insights from patients' experiences of living with a condition (and also from family members, caregivers, clinicians, healthcare providers and policy makers) • Identify issues and details that researchers may not have been initially aware of • Prevent missteps that might have derailed the research process • People are creative and can provide not only data but critical context and unique insights not obtainable through conventional approaches. • People are eager and able to solve problems when presented with the right tools and opportunities, not only technical tools and interfaces but approaches that enable creativity and insight. • It can point out research key priorities for society
Improve relations with patients	• Help to ensure that patient information sheets are legible, unequivocal, and easy to understand • Help to ensure that research procedures are admissible to participants • Increase volunteer enrolment and retention • Help to explore barriers and facilitators to their compliance/adherence to assessment and treatment methods • Improve quality of life of patients

	• Earlier diagnosis of diseases through awareness raising • Opportunity for sharing knowledge and experiences between patients (“from survivors to survivors”)
Impact of research	• Greater use and uptake of research findings by patients and stakeholders • Foster innovation in health • Bring meaningful outcomes that could meet patients’ expectations, needs and preferences • Ensure research findings are applicable to the patient experience, improving the usefulness of research • Research that is more meaningful and culturally/socioeconomically appropriate • Improve the dissemination of research findings • Garner the attention of policy-makers and other stakeholders for research
Economic benefits	• Funding for research (many funding organisations, such as the European Commission, increasingly require citizen engagement within their evaluation criteria; in the UK the NHS no longer funds clinical trials without patient engagement) • Reduce research costs (data collection by volunteers) • Reduce health care costs (more suitable and effective treatments)
For the researcher	• Enhance the opportunities to have funding applications approved • Receive positive evaluations in institutions that follow the CoARA principles of researcher evaluation: openness, which “corresponds to early knowledge and data sharing, as well as open collaboration including societal engagement where appropriate”

Sources: Arumugam et al., 2023; Mintz e Couch, 2022, interviews with citizen science practitioners

At the roundtable on citizen science in health during the Encontro Nacional de Ciência Cidadã (Oeiras, November 2025), the audience was asked, through Menti, why do citizen science in the health sciences? (Figure). The answers highlighted mainly its role in promoting awareness and empowerment, but also knowledge and literacy, evidence-based medicine and prevention.

Figure 2. Why do citizen science in the health sciences?

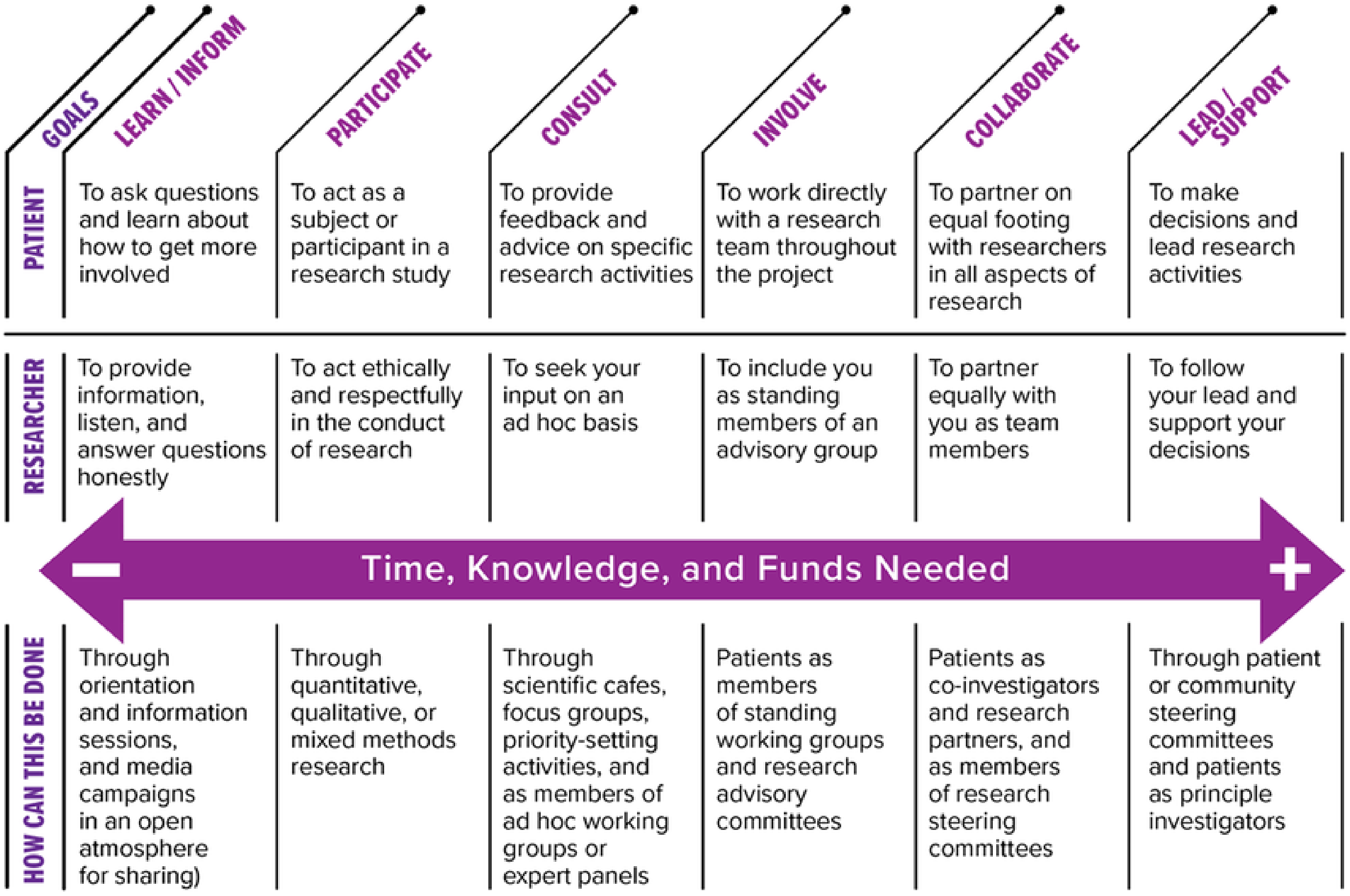
Source: Menti, Encontro Nacional de Ciência cidadã, Oeiras, November 2025

Levels and types of citizen/patient engagement

> *"There is no one-size-fits-all approach to patient engagement."*
> (Edwards et al., 2021, p. 1).

Citizen science is but one of the types of engagement of citizens and patients with research. Following the lead of the "ladder of engagement" devised by Arnstein (1969), several authors have proposed typologies of engagement in health research that range from the less demanding in terms of time and resources (inform and consult) to the more intensive (actively engage citizens/patients in scientific research) (Figure 3).

Figure 3. Levels of patient and researcher engagement in health research.



GOALS	LEARN / INFORM	PARTICIPATE	CONSULT	INVOLVE	COLLABORATE	LEAD / SUPPORT
PATIENT	To ask questions and learn about how to get more involved	To act as a subject or participant in a research study	To provide feedback and advice on specific research activities	To work directly with a research team throughout the project	To partner on equal footing with researchers in all aspects of research	To make decisions and lead research activities
RESEARCHER	To provide information, listen, and answer questions honestly	To act ethically and respectfully in the conduct of research	To seek your input on an ad hoc basis	To include you as standing members of an advisory group	To partner equally with you as team members	To follow your lead and support your decisions
HOW CAN THIS BE DONE	Through orientation and information sessions, and media campaigns in an open atmosphere for sharing)	Through quantitative, qualitative, or mixed methods research	Through scientific cafes, focus groups, priority-setting activities, and as members of ad hoc working groups or expert panels	Patients as members of standing working groups and research advisory committees	Patients as co-investigators and research partners, and as members of research steering committees	Through patient or community steering committees and patients as principle investigators

Source: Manafo, Petermann, Mason-Lai, and Vandall-Walker, 2018

It is not necessary to involve patients/citizens in all stages of the research process, but informing and consulting them throughout the research project should be considered the minimum. There are advantages in having a deeper involvement, but it does depend on the research topic, aims and methodology. Also, the patients may not be interested in or available for engaging at a deeper level, so participation should not be forced. According to Del Savio et al. (2016, p. 1) even lower levels of participation (such as crowdsourcing) can help democratise science, by "foster[ing] dialogue between researchers and publics, and increase[ing] the influence of citizens on research agenda setting”. This can help identify projects that are relevant for citizens and influence the design of studies and research questions.

Even among citizen science projects with higher levels of citizens/patients engagement, there are variations. For instance, Wiggins and Willbanks (2019, p.5) distinguish between two types of citizen science projects:

- **Contributory citizen science projects** focus on engaging participants in a limited portion of the scientific research process, using a common citizen science model that “engages a dispersed network of volunteers to assist in professional research using methodologies that have been developed by or in collaboration with professional researchers” (Cooper et al. 2007, 2) in a top-down structure, with the explicit expectation that volunteers are involved primarily in data collection to address researchers’ questions.
- **Co-created citizen science** applies a very different strategy, with members of the public (usually framed as a community) engaged in most or all of the scientific inquiry process, with or without the involvement of a professional scientist. These projects often take on a bottom-up or grass-roots structure and a substantively different approach from conventional science

King et al. (2019), drawing from Bonney et al. (2009), propose a three-tiered typology of citizen science in the health sciences, distinguishing between contributory, collaborative and co-created approaches (Box 4).

Box 4. Types of citizen science in the health sciences.

For the people - Contributory

- donating of biological samples and other person-level health information gathered from individuals
- utilizing available online social media and other “big” data for free-living, population-level surveillance of health behaviors or disease outcomes

With the people - Collaborative

- actively collecting data in the advancement of science
- collecting continuous individual behavioral and physiological data through wearable devices and sensors
- crowdsourcing information to benefit science and/or the larger community, through games or citizen reporting of local conditions that can negatively impact health

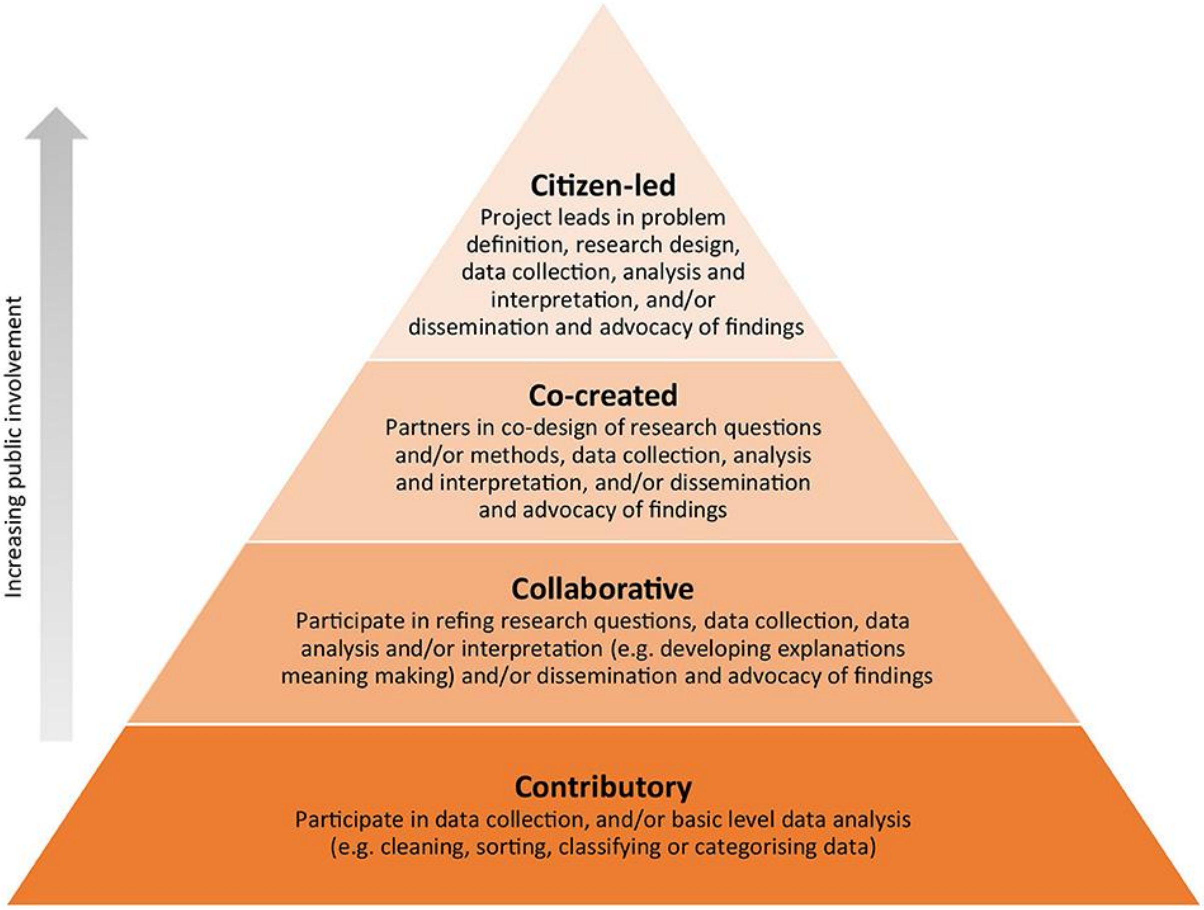
By the people - Co-creation

- catalyzing changes in local environmental and social drivers of health
- engaging in question identification and project planning in ways that help to ensure the relevance of the scientific endeavor to the health of their communities

Source: King et al., 2019

Finally, Marks et al. (2022) expanded the typology by adding an additional top layer: citizen-led projects (Figure 4).

Figure 4. Four models of citizen science characterized by increasing levels of public involvement in the research process.

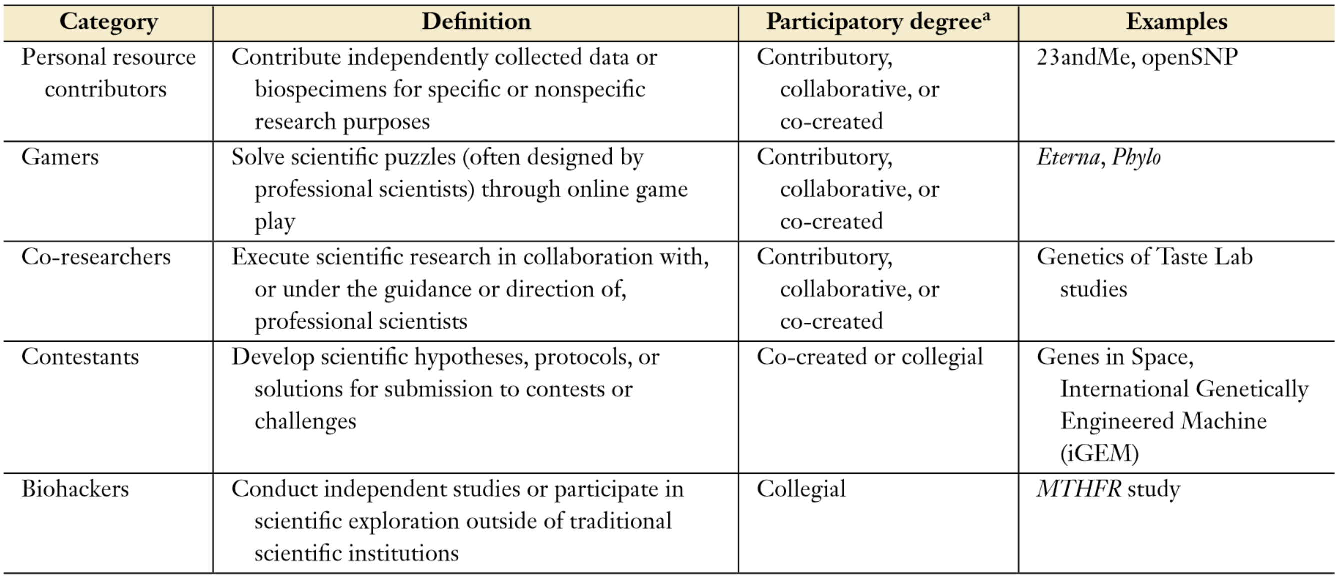


Source: Marks et al. 2022. Adapted from Den Broeder et al. (2018) and English et al. (2018)

Moreover, citizens/patients can play different roles within these research projects. For Arumugam et al. (2023, 6), patients and citizens can be involved as an “object/ respondent, advisor, interviewer/moderator, research partner and research principal”.

Finally, different disciplines within the health sciences may encourage different levels and types of engagement. For instance, Guerrini and Contreras (2020) focusing on genomics, identified five distinct types of citizen scientists active in this field.

Table 2. Typology of genomic citizen scientists.

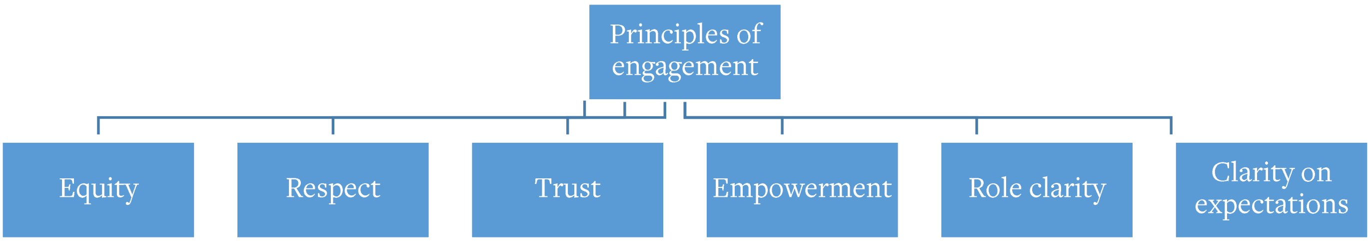


Category	Definition	Participatory degree[a]	Examples
Personal resource contributors	Contribute independently collected data or biospecimens for specific or nonspecific research purposes	Contributory, collaborative, or co-created	23andMe, openSNP
Gamers	Solve scientific puzzles (often designed by professional scientists) through online game play	Contributory, collaborative, or co-created	*Eterna*, *Phylo*
Co-researchers	Execute scientific research in collaboration with, or under the guidance or direction of, professional scientists	Contributory, collaborative, or co-created	Genetics of Taste Lab studies
Contestants	Develop scientific hypotheses, protocols, or solutions for submission to contests or challenges	Co-created or collegial	Genes in Space, International Genetically Engineered Machine (iGEM)
Biohackers	Conduct independent studies or participate in scientific exploration outside of traditional scientific institutions	Collegial	*MTHFR* study

Source: Guerrini and Contreras 2020

Regardless of the type and level of engagement some general principles should guide interactions between researchers and patients/citizens (Figure 5). Arumugam et al. (2023), for example, highlight principles such as equity, mutual respect, trust, empowerment, role clarity (who should do what) and clarity on expectations.

Figure 5. Principles of engagement.



Source: Arumugam et al., 2023

When to engage citizen scientists in research?

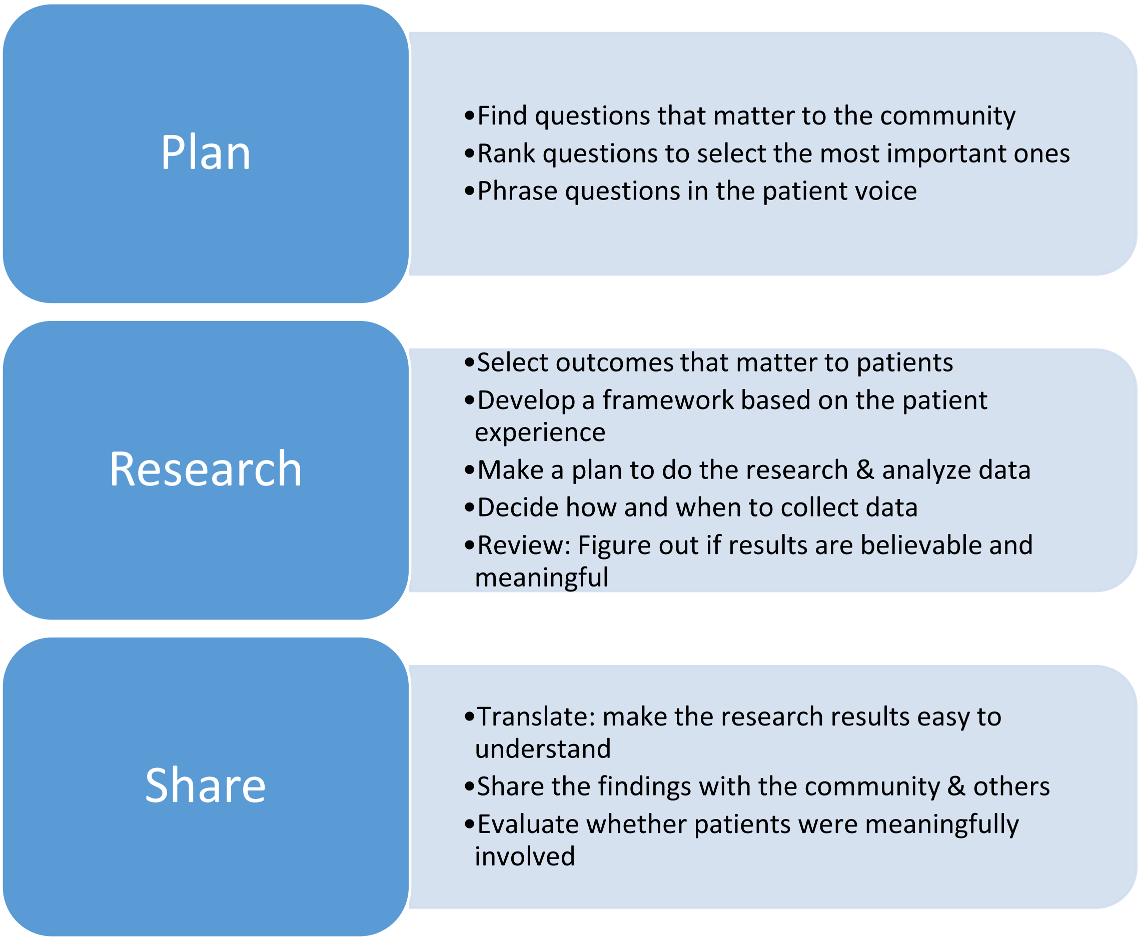
> *“Participation is not static, it´s fluid.” (interview with practitioner)*

Ideally, in citizen science projects, citizen/patients should be involved at all stages of the research process, from defining the topic of research to disseminating the results. However, this is not always feasible nor even appropriate to all cases.

On the one hand, the complexity of the research topic and methodologies may limit the extent to which citizens and patients can be directly involved. On the other hand, their involvement also depends on the budget of the projects. There are specific costs associated with different aspects of participation, including recruitment, training, providing tools and equipment, rewards, travel for events, etc. Furthermore, few dedicated lines of funding for citizen science activities exist, although general funding programmes accept citizen science proposals (e.g. European Framework Programme, ERC, FCT) and some activities are supported by programmes such as Ciência + Cidadã in Oeiras.[3]

Despite these limitations, it is still possible, and often valuable, to involve patients at different points in the research process. Edwards et al. (2001) identify the activities in which patients can participate in the three main stages of the research process: planning, researching and dissemination (Figure 6).

Figure 6. Patient engagement activities in the research process.



Plan

- Find questions that matter to the community
- Rank questions to select the most important ones
- Phrase questions in the patient voice

Research

- Select outcomes that matter to patients
- Develop a framework based on the patient experience
- Make a plan to do the research & analyze data
- Decide how and when to collect data
- Review: Figure out if results are believable and meaningful

Share

- Translate: make the research results easy to understand
- Share the findings with the community & others
- Evaluate whether patients were meaningfully involved

Source: Edwards et al. 2021 (adapted)

Building on the recommendations of the Patient-Centered Outcomes Research Institute, the same authors also offer a comprehensive picture of how patients can be involved in different stages of the research process (Figure 7).

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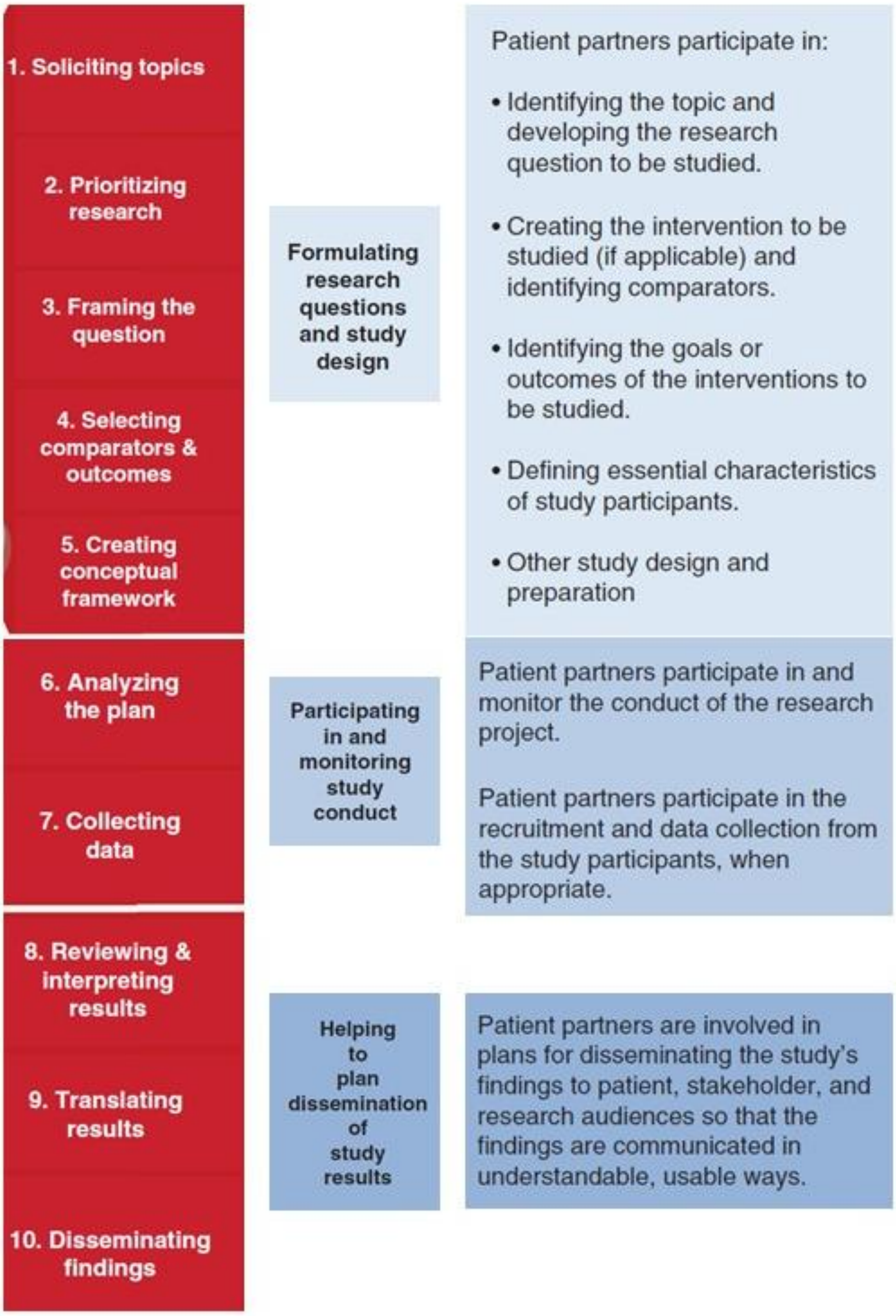
[3] https://www.oeiras.pt/programa-ciencia-mais-cidada

Figure 7. Involving patients in the research process.



Patient partners participate in:

- Identifying the topic and developing the research question to be studied.
- Creating the intervention to be studied (if applicable) and identifying comparators.
- Identifying the goals or outcomes of the interventions to be studied.
- Defining essential characteristics of study participants.
- Other study design and preparation

Patient partners participate in and monitor the conduct of the research project.

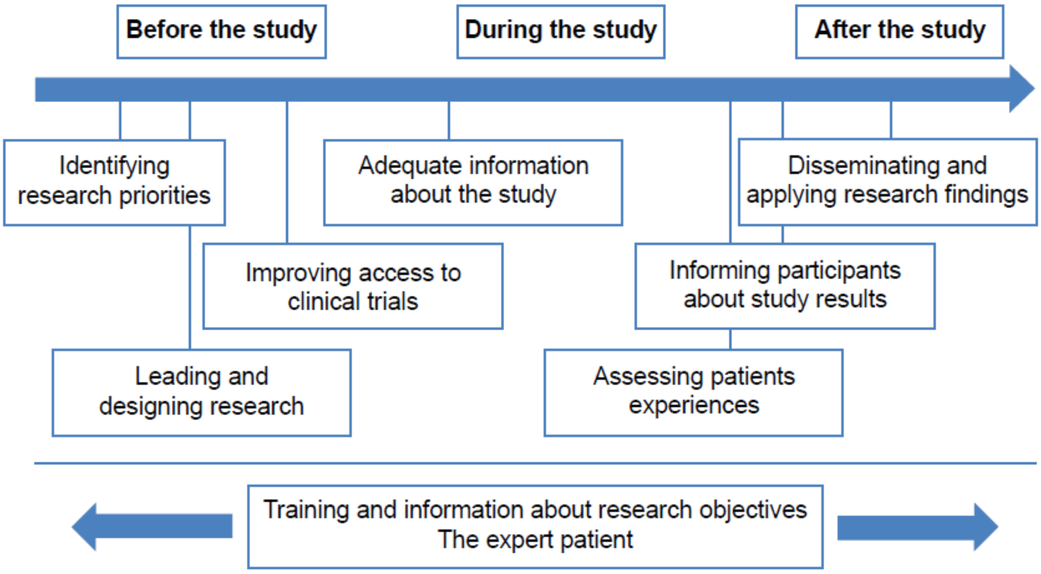
Patient partners participate in the recruitment and data collection from the study participants, when appropriate.

Patient partners are involved in plans for disseminating the study's findings to patient, stakeholder, and research audiences so that the findings are communicated in understandable, usable ways.

Source: Adapted from Edwards et al. 2021

Sacristan et al. (2016) address more specifically the stages of clinical research but focus also on patient engagement rather than citizen engagement (Figure 8).

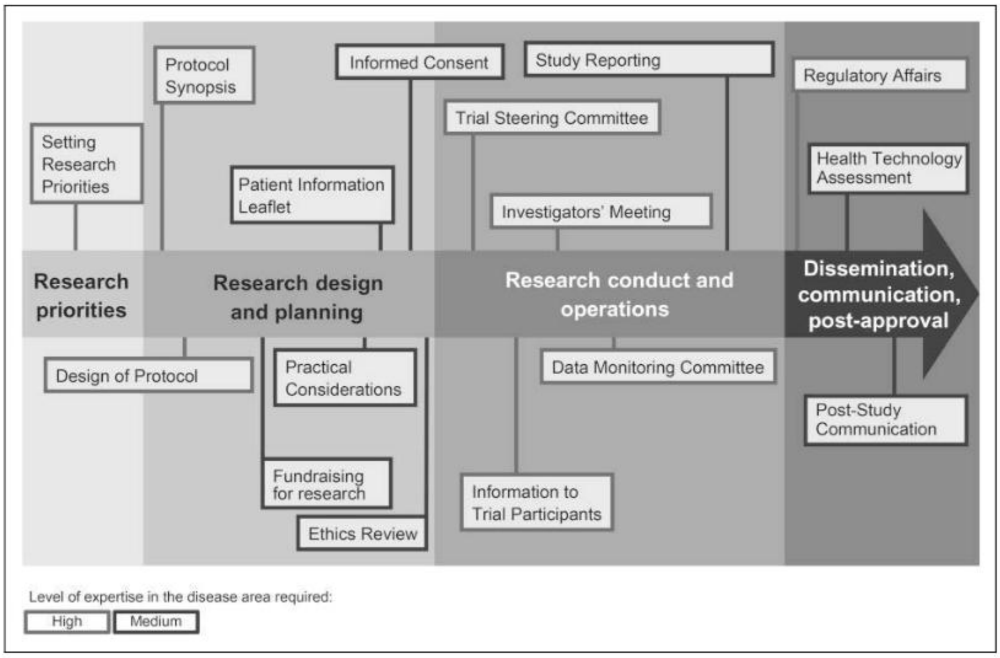
__Figure 8. Engagement of patients in clinical research.__



Source: Sactistan et al. 2016

Geissler et al. (2017) developed a very useful roadmap for patient involvement applicable to the development of new medicines. Figure 9 and Table 3 describe the main activities for patient involvement along the stages of the research process.

__Figure 9. Patient involvement across the medicines R&D process.__



Source: Geissler et al. 2017

Table 3. Patient Involvement Activities Across the Medicines R&D Process.

Setting research priorities:	• Gap analysis • Early horizon scanning • Matching unmet patients' needs with intended research outcomes • Defining patient-relevant added value and patient-relevant outcomes»
Research design and planning	• Protocol design and synopsis: relevant endpoints, inclusion and exclusion criteria, target population; diagnostic procedures; patient-reported outcome / quality of life measures; risk-benefit balance; crossover; ethical issues; mobility issues; data protection • Fundraising • Informed consent and patient information: content, visual design, readability, language • Ethics review
Research conduct and operations	• Investigators Meeting: patient perspective on trial, recruitment, challenges, opportunities, can trigger amendments • Trial Steering Committee and Data Monitoring Committee: eg, for risk/benefit, drop-out issues, amendments • Information to participants: protocol amendments, new safety information • Improving patient access to trials
Dissemination, communication, post-approval	• Regulatory affairs: EPAR summaries, package leaflets, updated safety communications and other finding in real world use (eg, how to inform and communicate issues or opportunities based on real world usage with a non–clinical trial setting population) • Establishing/designing phase IV (pharmacovigilance) studies data collection and communications • Creation of lay summaries (as required by the EU Clinical Trial Register) • Contribution to publications and dissemination of research results to patient community and professional communities • Health Technology Assessment: assessment of value, patient-relevant outcomes, priorities

Source: Geissler et al. 2017.

Involving patients/citizens at different stages of the research process presents both opportunities and challenges.

<u>Early stages: defining research questions:</u>

Engaging citizen scientists in the definition of the research topic and question is one of the most common practices in patient engagement and one of the easiest to accomplish. However, it can be problematic for funding applications, that usually require a clear definition of objectives and methods.

Manafò et al. (2018, p. 12) issue a set of recommendations for the engagement of patients and citizens in priority setting in research:

i) Timeframe: build realistic timeframes, including a research design stage which offers public involvement for at least two weeks to read, clarify, and provide feedback on the process;

ii) Visibility: Make any public contributions visible; be transparent about how the public has been involved;

iii) Accessibility: The public members involved in the research design stage require information, as do the rest of the research team, but communicated in way that they can access and understand, using plain language.

Data collection and analysis:

At the data collection stage, Wiggins and Willbanks (2019) define two types of tasks in which citizens can be involved:

- Data collection: observational studies of, for instance, personal health data, microbiomes, and sensory pollution
- Data processing: apply a contributory model (due to the reliance on purpose-built tools and data sources) and focus on harnessing human attention at scale, for instance using video games to support puzzle-based problem solving, a cognitively intensive task

However, to ensure data quality, citizen scientists must be properly trained in data collection methods (e.g. applying questionnaires, doing interviews, collecting samples, self-tracking). While this may raise questions about the validity and quality of data (a common criticism of citizen science), protocols should be in place to verify both and all information collected should be reviewed by a scientist. It is sometimes advisable to start with a pilot to test procedures and materials before expanding the participation and scope.

Dissemination and communication:

Citizen or patient involvement in dissemination is particularly valuable, not only in presenting results at scientific conferences to inspire other researchers but also in communicating findings to stakeholders and policy-makers. This adds legitimacy by combining scientific expertise with lived experience. The involvement of citizens/patients also helps with the "translation" of results into a more accessible language and with prioritising results that are more relevant to address the needs and concerns of patients. One such example are Evidence Summaries for Citizens, where summaries of research results in simple, acronym-free language and attractive visuals are co-created and co-validated with groups of citizens (Silva et al. 2025).

Box 5 provides two examples of research projects incorporating citizen science at different stages of the research process.

Box 5. Examples of citizen science projects in the health sciences.

Example 1: citizen science project with cystic fibrosis patients (Heyen et al., 2022):

1. scientists and patients defined the research question, through a 2-day workshop (co-creation), with evaluation of various topics and voting

2. scientists and patients developed a questionnaire on patients' daily problems (which then obtained ethics board approval)

3. the online survey with patients was applied through the association, patients wrote the recruitment texts

4. in the data analysis, scientists carried out statistical analysis, patients identified key findings

Funded by the European Union

5. dissemination and exploitation of results through online symposium, conferences, articles, with patients as co-authors

Example 2: citizen science project with healthy citizens in a translational medicine clinical experiment on non-alcoholic fatty liver disease (Shah et al., 2023):

1. Citizen scientists involved in the co-design and/or review of data collection tools (e.g., semi-structured open-ended questionnaire surveys and semi-structured wellbeing diaries completed by the participants)

2. Co-analysis of data on participants’ experiences and motivations

3. Co-drafts of research findings and papers

4. Suggestions for policy recommendations

Who should be engaged?

Citizen science projects in the health sciences involve two main types of participants:

- Patients, carers, patient associations
- Healthy citizen volunteers

The first group tends to have intrinsic motivation for participating in these types of projects: to help find a cure or an effective treatment, to alleviate suffering, to learn how to manage better the disease, or to advocate for their interests and influence agenda setting. It is likely that they would agree to more intensive or demanding forms of participation (for instance, providing samples with more invasive procedures, to answer longer or more frequent questionnaires) within citizen science projects. Patients, caregivers, those affected by health challenges, and healthy individuals may be highly motivated to collect and share personal health data in support of research that helps others with similar circumstances (Arumugam et al., 2023)

The second group can also be motivated by health concerns (getting a diagnosis or a health evaluation, learning about symptoms or preventive behaviours), but will likely accept more willingly less demanding tasks.

Both groups can be quite diverse internally and that should be taken into account in recruitment: including children, young people, adults, older people and families.

When engaging patients, it is important that the research makes use of the patients’ expertise of living with the disease (in what can be called “patient science”, Heyen et al., 2022, p. 1). This is particularly relevant, for instance, in projects that develop technologies or recommendations for treatment adherence or in designing information materials for other patients and care-givers.

The patient’s state of health should be considered when defining their roles and contributions. It is possible that throughout the project their capacities and availability may be variable, according to the evolution of the disease. Moreover, not all patients are willing participants in projects of this type, some may just want to see their health problem addressed without further engagement, while others may fear being stigmatised.

Involving both individual patients and patients’ associations does not always work well. Members from patient associations tend to be more informed, with higher levels of formal education and can be considered “expert patients”. Their experiences may not be representative of the wider patient population and they may be more vocal and dominant, unintentionally silencing other voices. As such, they ought to be considered preferentially as stakeholders rather than citizen scientists and involved in different types of activities.

It is well known that participation is not equally distributed across society: “although citizen science has the potential to make biomedical research more inclusive, the benefits of current citizen science initiatives are not equally accessible for all people—in particular those who are resource-poor, located outside of traditional networks of healthcare services, or members of minorities and marginalised groups.” (Fiske et al. 2019b, 617). Citizens/patients with lower educational attainment levels are usually more difficult to engage, since they tend to self-exclude, believing that they do not have a valid contribution to give or do not have the skills to provide a meaningful participation.

However, there is a strong argument to be made for increasing the representativeness and diversity of participants in citizen science projects in the health sciences, so that different contextual factors and lived experiences are taken into account. Efforts should aim not only to achieve gender balance but also to include participants from different social groups, ethnical backgrounds, and with disabilities.

Furthermore, citizen science projects in the health sciences often need to involve also other types of actors: healthcare workers and professionals, physicians, nurses, therapists, administrators, medical students, designers, politicians, etc.

How to recruit citizen scientists?

A crucial stage in citizen science projects is the recruitment of citizens to participate in the research.

Arumugam et al. (2023) propose a checklist to guide the recruitment of patients in research projects, which includes:

(1) the role of patient research partners

(2) phase of involvement

(3) the recommended number

(4) recruitment

(5) selection

(6) support

(7) training

(8) acknowledgement

Different strategies may be required in order to recruit patients and citizens (Table 4).

Table 4. Strategies for recruiting patients and citizens for citizen science projects.

Recruiting patients	*Recruiting citizens*
Patient associations Physicians, nurses and other health care providers Participation/Patients/Citizens offices in hospitals and health centres Snowballing	Partnerships with national/local authorities, companies, schools and civil society organisations Database of volunteers for clinical research Media Online and social media Hiring a marketing company Outreach events Snowballing

In the case of hard-to-reach communities, it is advisable to work with mediators and gatekeepers (community leaders, religious figures, local authorities) to recruit participants to citizen science projects.

Another crucial aspect of recruitment is the use of incentives, that should be well defined and communicated in advance. Below are a few examples of what can be offered in return for the participation of citizen/patient scientists:

- Thank you letter or certificate
- Acknowledgement of contribution in research outputs
- Information on research results and outcomes
- Information on personal health status, comparison with reference samples, or diagnosis
- Recommendations for improving health and prevent disease (diet, lifestyle)
- Fast-tracking for medical appointments
- Inclusion in dissemination activities, as spokespersons for the project
- Invitation to outreach events (i.e. lab visits, exhibitions, conferences)
- Food and drink (in events such as workshops)
- Paid expenses (e.g. transport, accommodation)
- Merchandising (notebooks, pens, T-shirts)
- Vouchers and tokens (e.g. museum tickets, book tokens)
- Devices necessary for participation (e.g. a cell phone to collect data or answer surveys that participants get to keep at the end of the project)
- Payment for participation

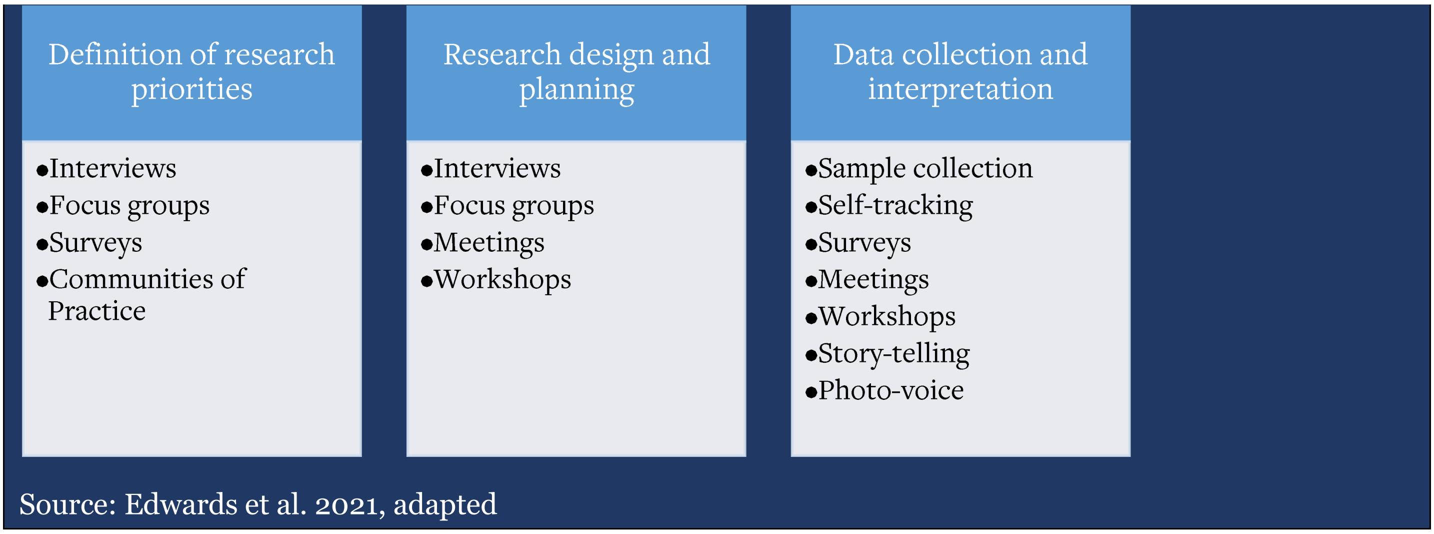
Paying participants is the most controversial form of reward, since it can induce bias and it may attract individuals with low motivation and weak engagement. However, it can be suitable if participation requires significant time, effort or days off work. Also, it can help engage citizens from low income backgrounds, who are often underrepresented in these initiatives, therby increasing diversity and fostering inclusion.

What methods to use in engaging citizen scientists?

According to Edwards et al. (2021, p. 1), approaches and methods for engaging citizen/patients scientists “can – and should – be different depending on the type of study and numerous other factors, such as the target population, geography, healthcare setting and social determinants of health.”.

Involving patients/citizens in different stages of the research process requires specific methodologies. Box 6 presents some examples of methodologies that can be used in the definition of research priorities, in research design and planning and in data collection and interpretation, and dissemination. Table 5 provides a brief explanation of some of these methodologies.

Box 6. Examples of methods for engaging citizen/patients scientists according to the stages of the research process.



Definition of research priorities	Research design and planning	Data collection and interpretation
Interviews Focus groups Surveys Communities of Practice	Interviews Focus groups Meetings Workshops	Sample collection Self-tracking Surveys Meetings Workshops Story-telling Photo-voice

Source: Edwards et al. 2021, adapted

Table 5. Short description of methods.

Surveys	"A cross-sectional design in relation to which data are collected predominantly by questionnaire or by structured interview on more than one case (usually quite a lot more than one) and at a single point in time in order to collect a body of quantitative or quantifiable data in connection with two or more variables (usually many more than two), which are then examined to detect patterns of association. The survey researcher needs to decide what kind of population is suited to the investigation of the topic and also needs to formulate a research instrument (questionnaire) and how it should be administered (in person, by telephone, online)." (Bryman 2012)
Semi-structured interviews	"A context in which the interviewer has a series of questions that are in the general form of an interview schedule but is able to vary the sequence of questions. The questions are frequently somewhat more general in their frame of reference from that typically found in a structured interview schedule. Also, the interviewer usually has some latitude to ask further questions in response to what are seen as significant replies." (Bryman 2012)
Focus groups	"A form of group interview in which: there are several participants (in addition to the moderator/facilitator); there is an emphasis in the questioning on a particular fairly tightly defined topic; and the accent is upon interaction within the group and the joint construction of meaning." (Bryman 2012)
Workshops	"an arrangement whereby a group of people can learn, acquire knowledge, perform creative problem-solving, or innovate in relation to a domain-specific issue (...) 1) workshops are conducted by people with extensive knowledge of the domain-specific issue, while the participants are those working in the same domain with different experiences and/or from different areas of the domain; 2) workshops have pre-defined goals; and 3) workshops promote active and genuine participation. Furthermore, workshops provide opportunities for stakeholders from different areas of the field to work together on a pre-determined issue." (Ørngreen and Levinsen 2017)

Story-telling	“a method where people share their experiences with others by telling stories orally and through the use of photos, pictures, animation, videos, plays, poems, music, presentations, books and other written methods” (Edwards et al. 2021)
Photo-voice	“a tool to engage community members in communicating lived experiences and influence policy to help address their concerns, PV has arguably gained traction as an approach that engages service users in authentic and meaningful co-creation of their healthcare (…) By asking participants to capture photographs and retell lived experiences, PV can provide an inclusive and accessible alternative, welcoming service users and other stakeholders, to sharing knowledge and discussing salient individual, community and policy concerns” (Halvorsrud et al. 2022).

6.1 Monitoring and evaluation

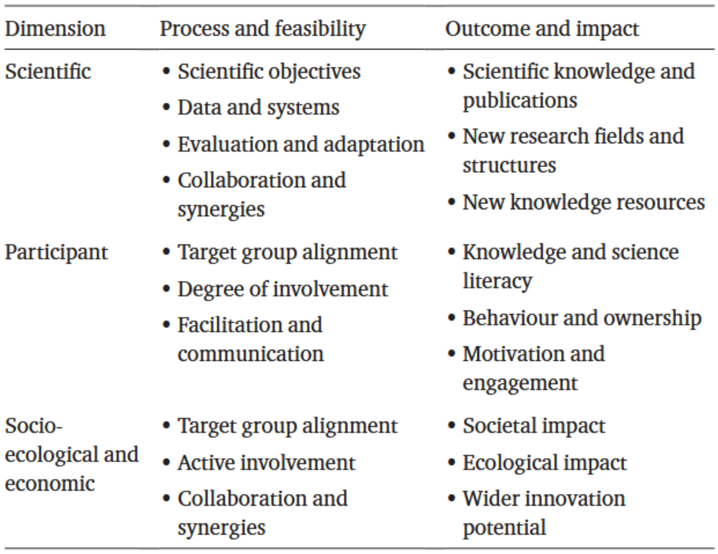
It is crucial to develop monitoring and evaluation tools in citizen science projects, to identify problems and mitigate them in future initiatives.

Particular attention should be paid to maintaining regular contact with citizen scientists and keeping them informed of the progress of the project. This can be done by phone, email, WhatsApp, website, blog, newsletter or in dedicated meetings and events. Such communication helps retaining their participation over time.

Asking regularly asking for citizen scientists’ feedback (i.e. opinion and suggestions about the information materials, protocols, instructions to collect samples, or list of invitees and programme of public events) helps improve the research process and also increases retention of participants. This can be done through both quantitative (surveys) and qualitative (interviews, focus groups) methodologies. The evaluation should include an assessment of whether expectations of participants were met and the impact of the citizen science project. Importantly, the evaluation of the experience of participants should not be restricted to citizens/patients. Researchers, stakeholders and mediators (e.g. medical practitioners that help recruit or monitor patients) should also be invited to provide feedback on the operation and outcomes of the project.

Kieslinger et al. (2018) have proposed an evaluation framework for citizen science that takes into account three dimensions (scientific, participant and socio-ecological and economic) and comprises both the process and feasibility and the outcome and impact of the project (Table 6).

Table 6. Citizen science evaluation framework.



Dimension	Process and feasibility	Outcome and impact
Scientific	• Scientific objectives • Data and systems • Evaluation and adaptation • Collaboration and synergies	• Scientific knowledge and publications • New research fields and structures • New knowledge resources
Participant	• Target group alignment • Degree of involvement • Facilitation and communication	• Knowledge and science literacy • Behaviour and ownership • Motivation and engagement
Socio-ecological and economic	• Target group alignment • Active involvement • Collaboration and synergies	• Societal impact • Ecological impact • Wider innovation potential

Source: Kieslinger et al. 2018, p.86

Regarding the impact assessment of citizen science projects, the ACTION methodology (developed by Passani et al. 2022) propose five areas of impact: scientific impact, social impact, economic impact, political impact and environmental impact (in the case of citizen science projects in this area). Each area has several dimensions operationalised in different variable indicators (Figure 10). In the case of citizen health sciences, the fifth area should be health impacts and could include dimensions such as contributions to the development of new drugs and treatments, to the improvement of existing treatments and public health, to diminishing morbidity and mortality. More information on the methodology can be found in the project deliverable.[4]

Figure 10 ACTION impact assessment methodology

Source: adapted from Passani et al. 2022

The ecs academy offers a two-hour free online course on Evaluation and Impact Assessment in Citizen Science Projects.[5] Another useful tool is the Citizen Science Appraisal Tool, a 16-question questionnaire developed by Wood et al. 2022 that can guide a project or study during its development stage and provide evaluation during implementation and after completion:

> *CSAT was developed to evaluate the quality of citizen science and other participatory approaches. Utilising a lifecycle approach, the CSAT evaluates a project or study starting with the aims through to outcomes and future impacts. The tool considers citizen science standards, participation, data quality and dissemination, which are elements of good quality citizen science. (…) A scoring system is employed to Evaluate the following three levels of engagement: contributory, collaboration and co-production[1,2], across: 1) Science and Research; 2) Leadership and Participation; 3) Data and delivery; and 4) Outcomes, evaluation and open data.*[6]

Ethics and data management

Ethics

Like all research projects in the health sciences, citizen science projects should also be subjected to stringent ethics considerations and authorisations.

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[4] https://doi.org/10.5281/zenodo.4432132

[5] https://moodle.citizenscience.eu/enrol/index.php?id=32

[6] https://www.birmingham.ac.uk/documents/college-les/2feb23-citizen-science-appraisal-tool.pdf

> Citizen Science initiatives, particularly in the biomedical sphere, bring with them the potential of (sometimes bodily) harm, and thus it is necessary to discuss ethical forms of evaluation for such initiatives. The plurality of interests at play in CS raises the possibility of conflicting aims, and clear analysis is needed to evaluate how these should be resolved. (Fiske et al., 2019, p. 17)

Ethical issues in citizen science depend on the tasks citizen scientists are called to perform, but also on research approaches (Wiggins and Willbanks 2019). They concern not just research methods and practices, but also "relational and moral complexities concerning collaboration, sharing power, and democratic decision-making" (Groot and Abma, 2022, p. 1)

The International Collaboration of Participatory Health Research has defined a set of Ethical Principles:

(1) mutual respect;

(2) equality and inclusion;

(3) democratic participation;

(4) active learning;

(5) making a difference;

(6) collective action; and,

(7) personal integrity

Concomitantly, Fiske et al. (2019) also highlight a list of ethical considerations particularly relevant to citizen science projects in the health sciences:

- social or scientific value
- return for the patient
- scientific validity
- fair selection of participants
- risk/benefit
- independent review
- informed consent
- privacy and data
- respect for the patient

When striving to include marginalised communities in citizen science, additional ethical issues arise. Fiske et al. (2019) emphasise the importance of addressing questions such as: who can participate, what are the barriers (financial, literacy), what are the costs, who should benefit, how are the results distributed, what data will be available, who does the data represent, recognising historical injustices, trust, global justice.

Gaining ethics approval for citizen science projects can be more complex than for conventional research, particularly because ethics committees may be unfamiliar with this model. Ethic approval procedures may differ depending on weather participants are patients or healthy citizens, and further distinctions may be needed within these groups (children, young people, family members, care givers, people with disabilities, people with cognitive impairments). It can also depend on the type of data being collected with/by citizen scientists (personal data, opinion surveys, biological samples). Different legal rules can also apply.

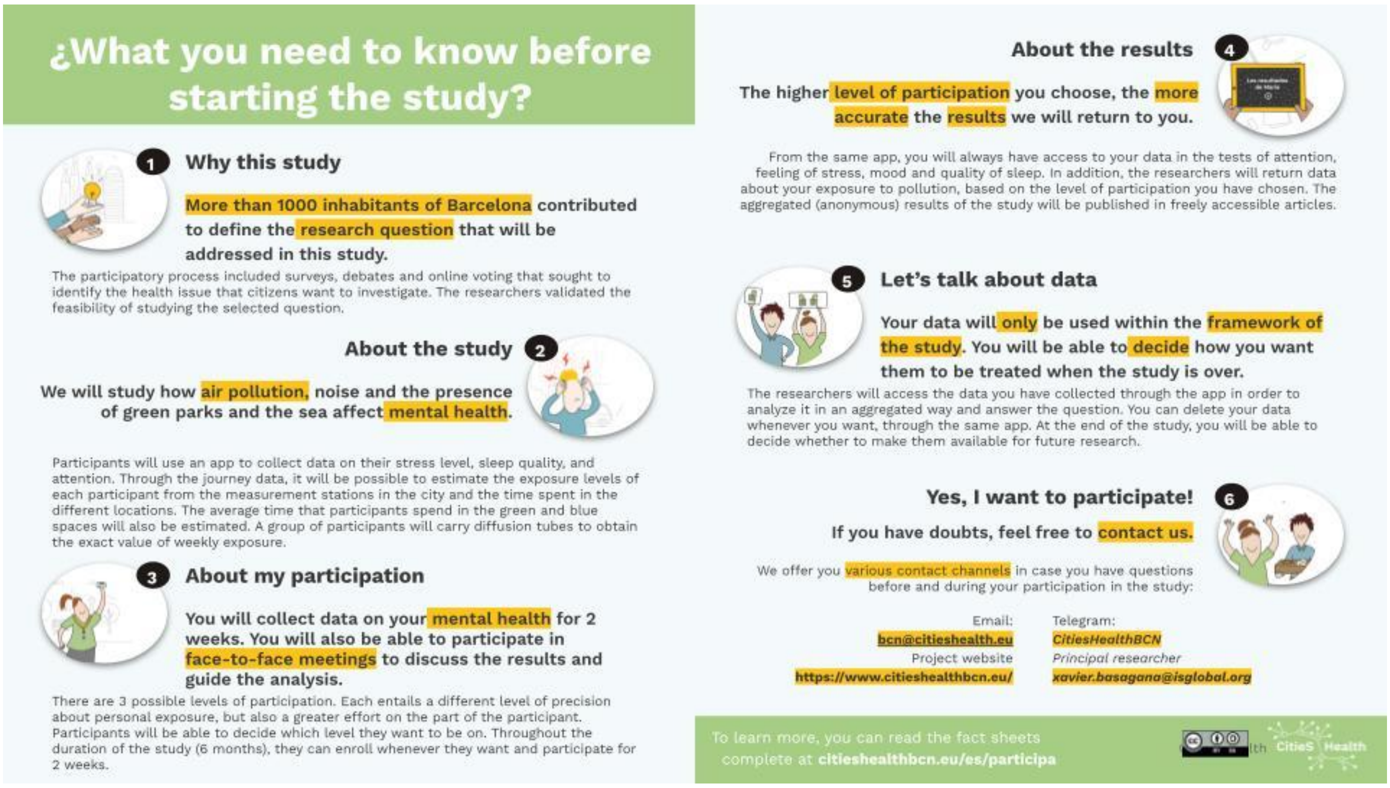
In some cases, citizens science in the biomedical sciences may require specific ethical authorisations that may fall outside the scope of universities or hospital ethics committees (e.g. projects that do not involve patients but healthy citizens instead). It is therefore necessary to identify who are the relevant authorities to seek permission from (e.g. DG Health, Ordem dos Médicos, Ministry of Education, etc.) and prepare specific ethics statements. It may be advisable to have preliminary meetings with these authorities to adjust ethics statements to their requirements. Importantly, potential delays in securing approvals should be factored into the project timeline.

Informed consent

Informed consent requires providing citizen scientists with two types of documents: an information sheet detailing all the relevant information regarding the project and a consent form, to be signed by both the researcher and the citizen scientist.

The information sheet should be as detailed as necessary, but it should also be clear and understandable by lay citizens. The European project Cities Health has developed a toolkit to design user-friendly citizen science information sheets: https://citizensciencetoolkit.eu/stories/citizen-science-information-sheet/ They have made available templates that can be customised by other projects, both of one-page information sheet (Figure 11) and full information sheets.

Figure 11. One-page information sheet template.



¿What you need to know before starting the study?

1 Why this study

More than 1000 inhabitants of Barcelona contributed to define the research question that will be addressed in this study.

The participatory process included surveys, debates and online voting that sought to identify the health issue that citizens want to investigate. The researchers validated the feasibility of studying the selected question.

About the study 2

We will study how air pollution, noise and the presence of green parks and the sea affect mental health.

Participants will use an app to collect data on their stress level, sleep quality, and attention. Through the journey data, it will be possible to estimate the exposure levels of each participant from the measurement stations in the city and the time spent in the different locations. The average time that participants spend in the green and blue spaces will also be estimated. A group of participants will carry diffusion tubes to obtain the exact value of weekly exposure.

3 About my participation

You will collect data on your mental health for 2 weeks. You will also be able to participate in face-to-face meetings to discuss the results and guide the analysis.

There are 3 possible levels of participation. Each entails a different level of precision about personal exposure, but also a greater effort on the part of the participant. Participants will be able to decide which level they want to be on. Throughout the duration of the study (6 months), they can enroll whenever they want and participate for 2 weeks.

About the results 4

The higher level of participation you choose, the more accurate the results we will return to you.

From the same app, you will always have access to your data in the tests of attention, feeling of stress, mood and quality of sleep. In addition, the researchers will return data about your exposure to pollution, based on the level of participation you have chosen. The aggregated (anonymous) results of the study will be published in freely accessible articles.

5 Let's talk about data

Your data will only be used within the framework of the study. You will be able to decide how you want them to be treated when the study is over.

The researchers will access the data you have collected through the app in order to analyze it in an aggregated way and answer the question. You can delete your data whenever you want, through the same app. At the end of the study, you will be able to decide whether to make them available for future research.

Yes, I want to participate! 6

If you have doubts, feel free to contact us.

We offer you various contact channels in case you have questions before and during your participation in the study:

Email: **bcn@citieshealth.eu**
Project website **https://www.citieshealthbcn.eu/**
Telegram: ***CitiesHealthBCN***
Principal researcher ***xavier.basagana@isglobal.org***

To learn more, you can read the fact sheets complete at **citieshealthbcn.eu/es/participa**

Source: CitiesHealth

There should be separate consent forms for patients involved in the study and for citizen scientists. In the case of minors, consent forms should be signed by both their parents or legal guardians and by the children or young people themselves (which requires specific formats adapted for this type of participant).

One effective way to build user-friendly information sheets and consent forms is by co-creating them with the participants in the study, both patients and citizen-scientists. This should be done in the early stages of the research process, through activities such as focus groups or workshops.

Data management and outputs

According to Borda et al. (2020) citizen science projects in health require a research data management model that is transparent and accessible to team members and to external audiences. This can be fostered by a participatory development of standards that can be applied to diverse projects and platforms, across the research data life cycle.

Another crucial point concerns privacy of information: citizen sciences and participants need to be assured that their data will be treated confidentially. Extra care should be taken in collecting personal data and in recording interviews (who will have access to the data, how will it be stored, whether will it be reused). Informed consent forms should cover all future uses of the data that is collected, who will have access to the databases (if they will be made available in open access). Researchers need to be aware of the type of data citizens are willing to share and under what conditions.

Some studies show that citizens are more motivated to participate in projects where data is shared with other researchers (open science) and not used for commercial purposes.

There may be divergences between scientists and citizens regarding data dissemination that need to be addressed. For example: citizens may want to disclose results and scientists may want to wait until they file patents or ensure they are the first to publish; scientists may want to disclose results and participants do not so as not to be stigmatised; citizens may advocate for open access data and scientists may want to restrict access until they have finished publishing (Guerrini and Contreras 2020).

Guerrini and McGuire, (2022, 8-12) propose an ethics framework for addressing the ownership of research outputs in medical citizen science projects. The framework includes the following dimensions:

- **reciprocal treatment** “considers whether a specific practice related to citizen scientists’ ownership of research outputs is fair given the quantity and/or quality of their research inputs.”
- **relative treatment**: “is a practice vis-à-vis some of a project’s citizen scientists too generous from the perspective of the project’s other citizen scientists given meaningful differences in their contributions?”
- **risk-benefit assessment**: “asks how citizen scientists will be impacted by a particular ownership practice, and like regulatory frameworks for evaluation of medical research protocols, aims to minimize anticipated harms to participants associated with the practice. It also takes into account potential offsetting benefits.”
- **reasonable expectations**: “asks whether the ownership practice is consistent with the reasonable expectations of citizen scientists that the project itself has generated. An ownership practice that does not satisfy this condition demonstrates disrespect by failing to make good on promises made or strongly indicated.”

Control of the decision over dissemination also should hinge on the degree of patient/citizen participation. When citizen scientists are just contributors of data, they may expect to have less control over these issues. When they act as co-researchers, involved in almost all stages of the research process “they deserve enhanced recognition in the form of, for example, opportunities for coauthorship or a say in the dissemination of outputs” (Guerrini and Contreras 2020, 473).

Including citizen scientists as authors of scientific publications (articles in journals or conference communications) has been done before (for instance, in astronomy papers), but it depends on the degree of involvement and contribution, as well as on the type of publication. This possibility should be negotiated in advance (in the recruitment stage and included in the informed consent) and the decisions should be communicated clearly. An alternative is to mention the contributions of citizen scientists in the acknowledgements section. In some studies, physicians that collaborated in recruiting and monitoring patients are also included as co-authors of the publications.

Including citizen scientists in patent registrations is more complex and largely unprecedented, due to financial and legal implications. But, again, this too should be negotiated in advance and the decisions should be communicated clearly.

Challenges

Despite all the benefits of citizen science in the health sciences mentioned above, a Best Practices document would be incomplete without mentioning the difficulties and hurdles.

According to Arumugam et al. (2023, p. 10), there are several challenges in patient participation and involvement in research:

> Firstly, difficulty with access to terminology, meetings and training along with communication challenges could affect the active involvement and contribution of PRPs. Secondly, change in the relationship between patient and researcher from traditional clinician-patient relationship into researcher-patient partner relationship could lead to exposure to unintended confidential information. Thirdly, uninformed assumptions of researchers about patient partners such as having inadequate knowledge and inadequate contribution could lead to tokenism. Lastly, apprehension of taking a new role as a research partner, inexperience with the technical terms, unclear role definition, and concerns regarding the ability to contribute among patients could affect the active involvement and contribution of patients as a partner in the research

Petersen et al. (2020, p. 2) also list several challenges for medical citizen science:

- technical issues: need for platforms, distributed networks, metadata collection, citizens' access to their own information, identification of barriers to data access
- organisational issues: respect for the agency of individuals, families and communities, ethical behaviour, new funding models, new research models, different participation models, importance of context
- collaborative issues: not seeing patients as collaborators, the need to train citizens, recruiting participants, participants with different skill levels, building trust

In addition, the literature and interviews with practitioners of citizen science point out to other recurring challenges:

- power asymmetry between researchers/medical professionals and patients/citizens
- risk of tokenism (making only a perfunctory effort or symbolic gesture toward the accomplishment of citizen/patient participation)
- difficulties in the retention of participants, keeping them engaged, ensuring they deliver the data/samples in a timely fashion
- the health situation of patients (some may be too ill to participate as expected)
- relationships with physicians and other healthcare professionals who help recruit patients (some more available and willing than others)
- relationship with collaborating health institutions (hospitals, health centres), study protocols should not require significant changes in the usual operation of these institutions
- citizen science as engagement with science and not production of new knowledge (data is not used for publication)
- citizen science may not yield publishable results (e.g. sample sizes not large enough, results not innovative enough.

Based on national and international experiences, citizen science projects require not just the goodwill or volunteerism of researchers, but rather strong institutional support structures and dedicated support staff, in the communications office, grants office, ethics office. In the case of VHIR, there is a Social Impact and RRI Strategy Responsible at the Internal Strategy Department, who supports researchers in preparing funding application that meet RRI criteria (including public engagement and citizen science) and also at the post-award stage, in organising the necessary activities.

Once these structures are in place, there are benefits in networking with other similar offices in other research institutions in the country, to share experiences, boost mutual learning and enhance collaborations.

When internal resources and support are scarce, another option for developing citizen science projects is to engage an external partner (company or research centre) that is responsible for the citizen engagement tasks. This is the case, for instance, of the European project GlycanTrigger, developed at I3S, that includes the company SPI Sociedade Portuguesa de Inovação as a partner for the social impact WP.

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Project name	**Institution**	**Participants involved**	**Brief description**	**Link**
Cell Spotting	University of Coimbra	Citizens	Game app where participants look at cancer cells to identify the efficacy of medicines	Article
Gripe.net	IGC; INSA	Citizens	Monitoring of the seasonal flu epidemic, based on the voluntary participation of citizens, who fill in weekly questionnaires. The project is integrated in an European network, Influenzanet.	Website
Microbioma Comunidade Portugal	GIMM/ITQB	Citizens	Sample collection from citizens to characterise the microorganisms (e.g. bacteria and fungi) that live in the intestines (microbiome) and their genetic	Project RNCC

			diversity over time, which is influenced by eating habits, lifestyles, antibiotic use and other factors.	
Diagnosing Obstructive Sleep Apnoea	Centro de Neurociências de Coimbra	Patients, workers in some occupations	Diagnosis of sleep apnoea through surveys of volunteers, workers in a bus company and in the municipal authority	Website
GlycanTrigger	I3S Instituto de Investigação e Inovação em Saúde	Patients	Investigate when, why and how changes in the intestinal glycoma trigger chronic inflammation; patient involvement through workshops and symposia	Website

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Examples of citizen science in health sciences in Portugal

For international examples, check the list maintained by the Working Group Citizen Science for Health of the European Citizen Science Association and the European Citizen Science Platform.

GIMM CARE contributes to a more coordinated clinical and translational research landscape in Portugal, supporting **innovative research that addresses concrete health questions** and generates **meaningful benefits for society**.

Background and Rationale

GIMM CARE is structured around four main pillars of activity:

1. **Mission-driven Research**: design and implementation of focused research and innovation projects;
2. **Training and Mentoring**: advanced modular programs for upskilling healthcare professionals and clinical researchers;
3. **Clinical Research Support**: professionalization of clinical studies and clinical trials management; preclinical acceleration;
4. **Next Generation Biobank**: biological samples and high-quality annotated data.

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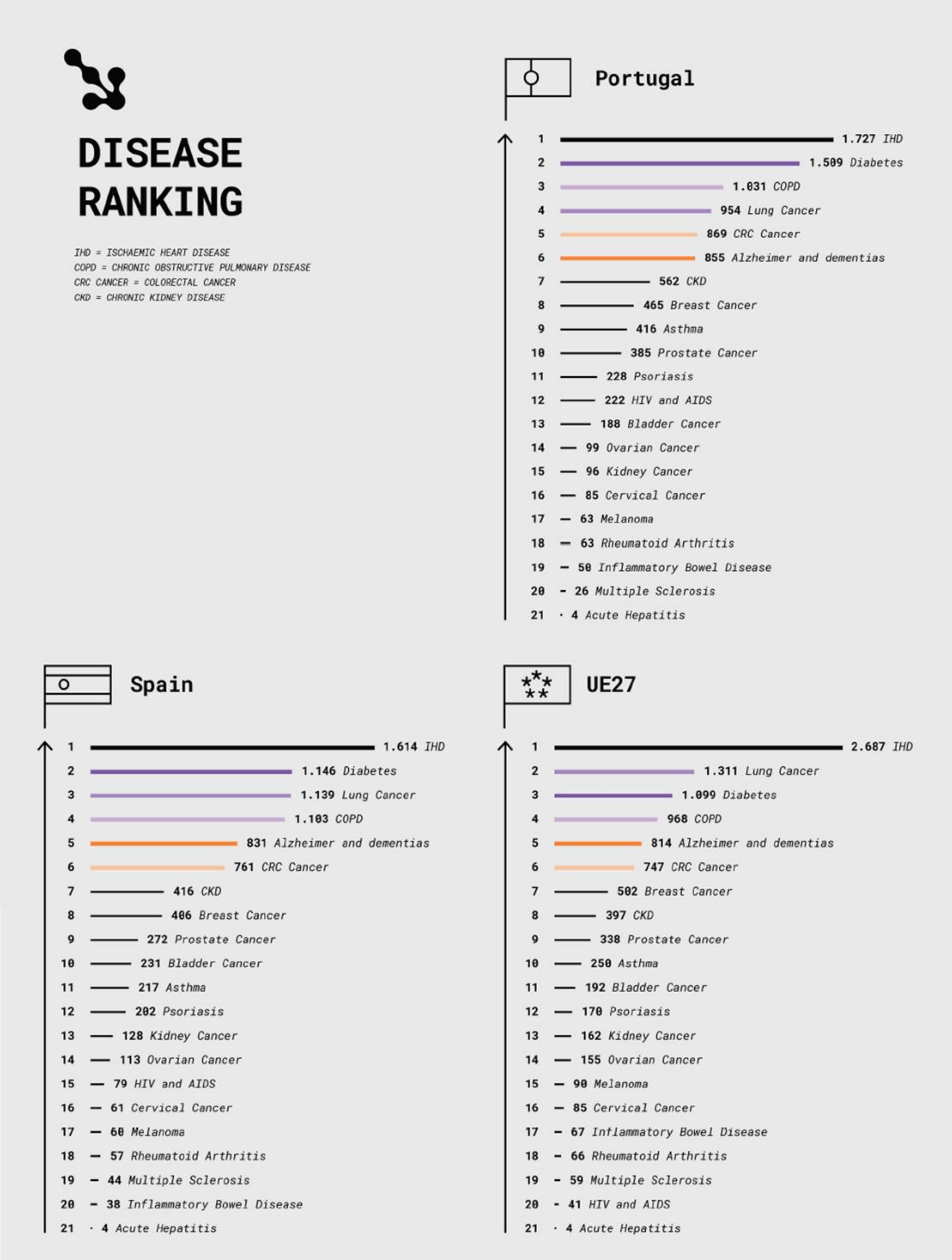
[7] https://www.pordata.pt/

[8] https://www.moai-consulting.com/



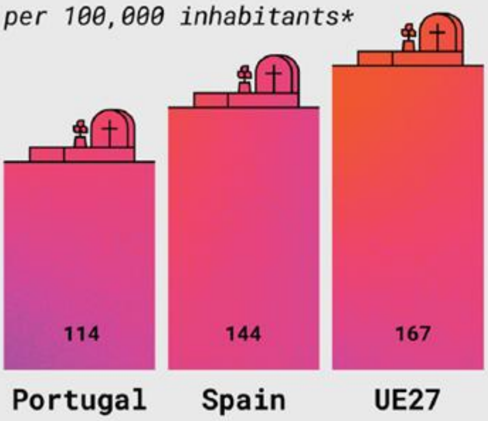
Funded by the European Union

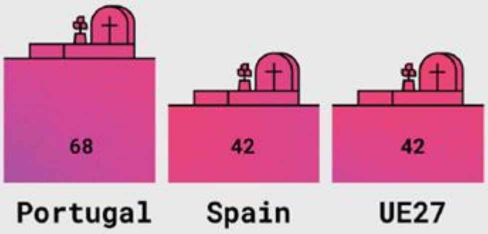
RISK FACTORS

SMOKING

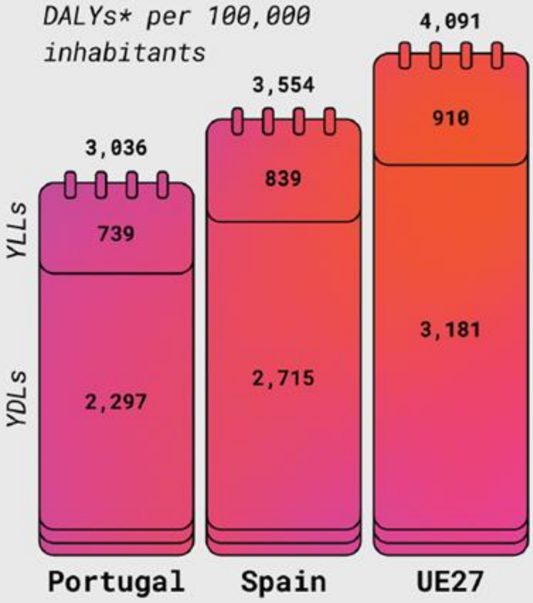
ALCOHOL CONSUMPTION

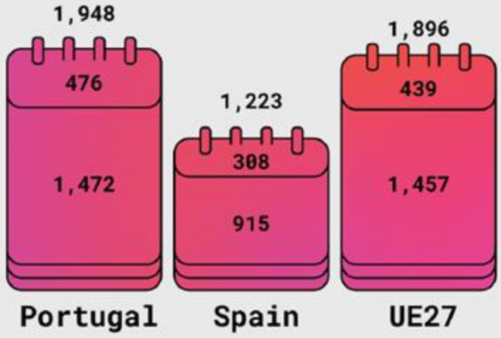
*Number of related deaths per 100,000 inhabitants**





DALYs per 100,000 inhabitants*





*THE NUMBER OF DEATHS SHOWN CORRESPONDS TO THE NUMBER OF DEATHS ATTRIBUTED TO EACH RISK FACTOR. THERE MAY BE A NUMBER OF RISK FACTORS THAT, WHEN TAKEN TOGETHER, INCREASE THE LIKELIHOOD OF A SICKNESS OR INJURY OCCURRING.

SOURCE: INSTITUTE FOR HEALTH METRICS AND EVALUATION, 2019 GLOBAL BURDEN OF DISEASE

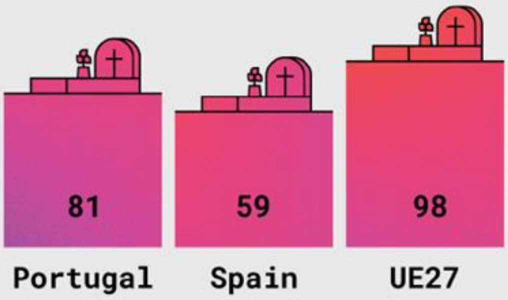
Funded by the European Union

RISK FACTORS

Physical activity and high cholesterol

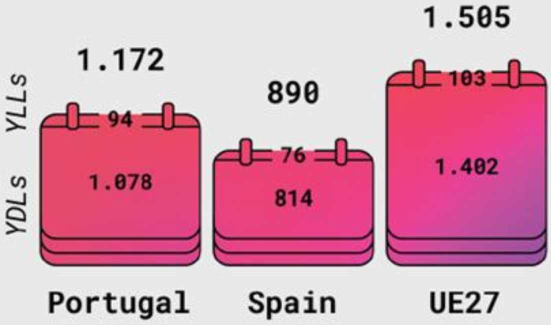
HIGH CHOLESTEROL

*Number of related deaths per 100.000 inhabitants**



*THE NUMBER OF DEATHS SHOWN CORRESPONDS TO THE NUMBER OF DEATHS ATTRIBUTED TO EACH RISK FACTOR. THERE MAY BE A NUMBER OF RISK FACTORS THAT, WHEN TAKEN TOGETHER, INCREASE THE LIKELIHOOD OF A SICKNESS OR INJURY OCCURRING.

DALYs per 100.000 inhabitants*

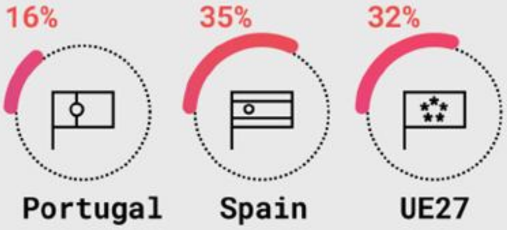


*DALYS, OR DISABILITY-ADJUSTED LIFE YEARS, ARE USED TO MEASURE THE BURDEN OF DISEASE, INJURY, AND RISK FACTORS ON POPULATIONS. ONE DALY REPRESENTS A YEAR OF HEALTHY LIFE LOST DUE TO PREMATURE DEATH OR DISABILITY.

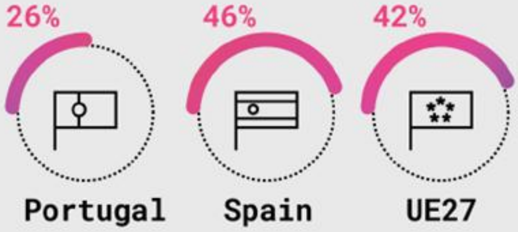
LACK OF PHYSICAL EXERCISE

% of population spending at least 150 minutes per week on physical activity

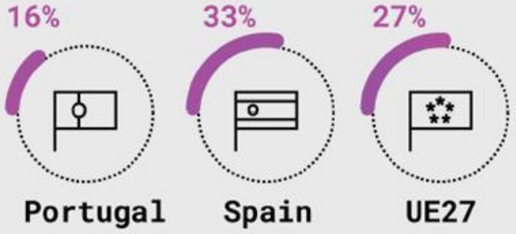
% from total population



% with tertiary education



% without tertiary education

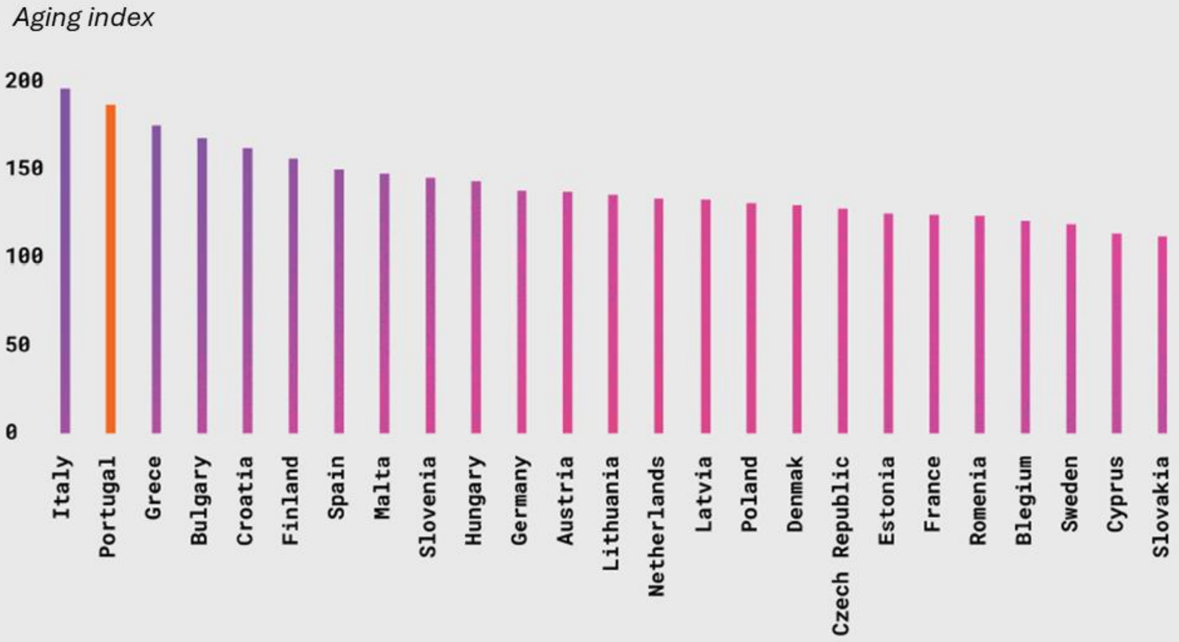


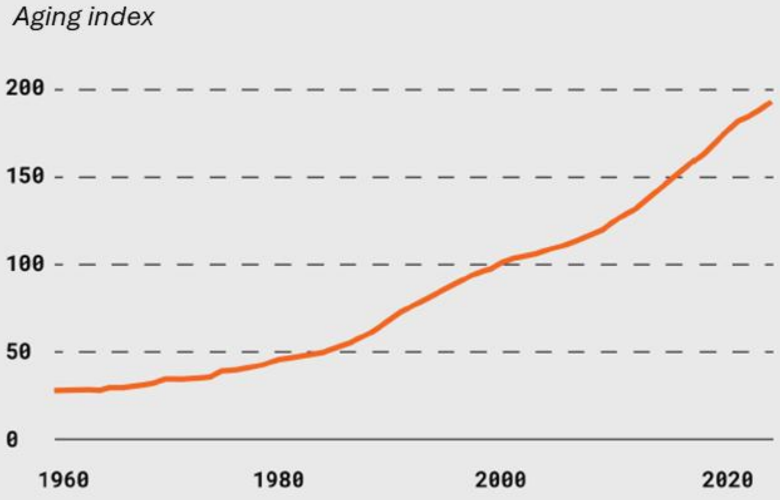
SOURCE: INSTITUTE FOR HEALTH METRICS AND EVALUATION, 2019 GLOBAL BURDEN OF DISEASE, HEALTH AT A GLANCE 2022

Funded by the European Union

PORTUGAL HAS THE SECOND HIGHEST RATIO OF OLDER PEOPLE VS YOUNGER PEOPLE IN THE EU

Over 65s per 100 young people





The ratio evolution in Portugal:

2024

192.4	100
Older	Younger

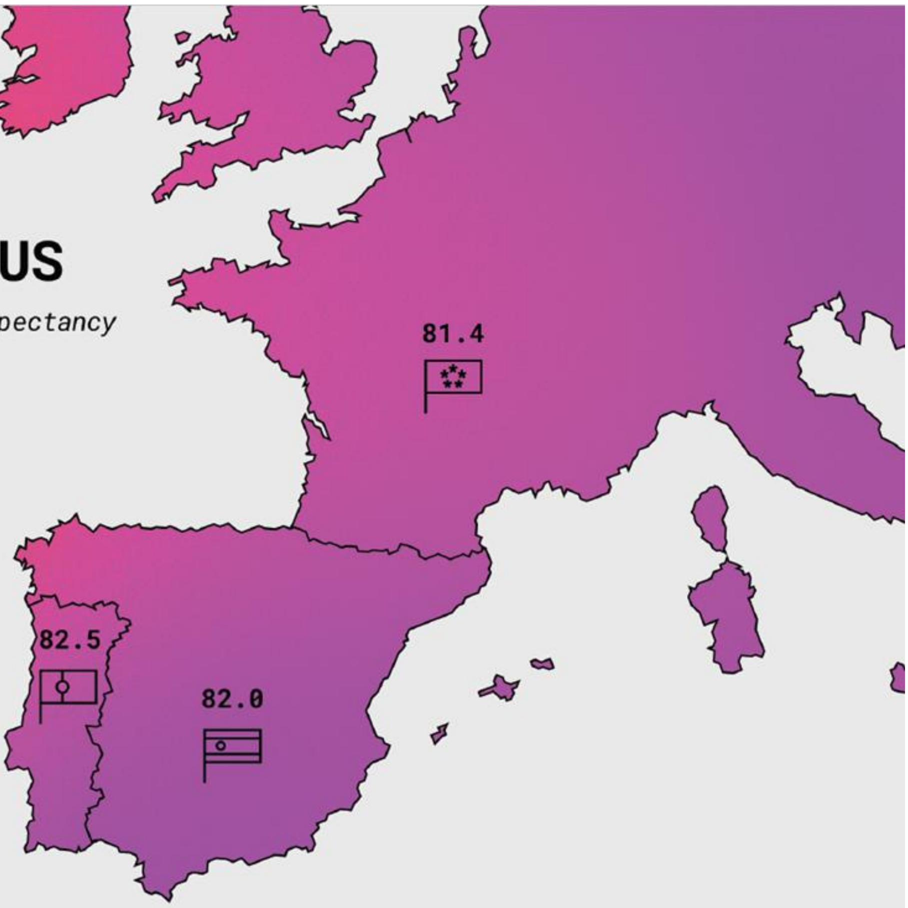
A 4.3 points increase from 2023

SOURCE: PORDATA

HEALTH STATUS

Life and healthy life expectancy

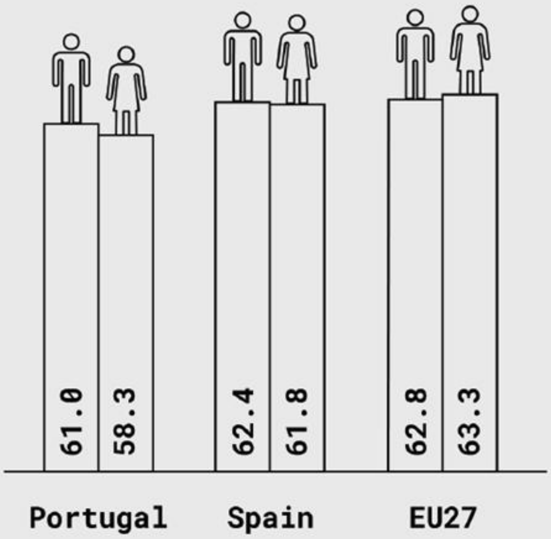
LIFE EXPECTANCY



HEALTHY LIFE EXPECTANCY

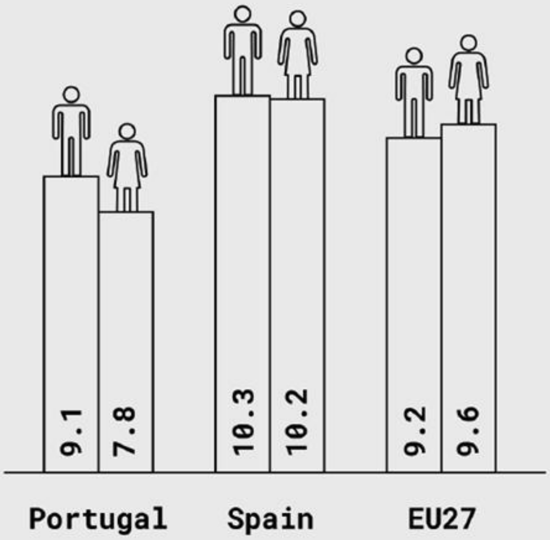
At Birth

Number of healthy years



At 65

Number of healthy years after 65



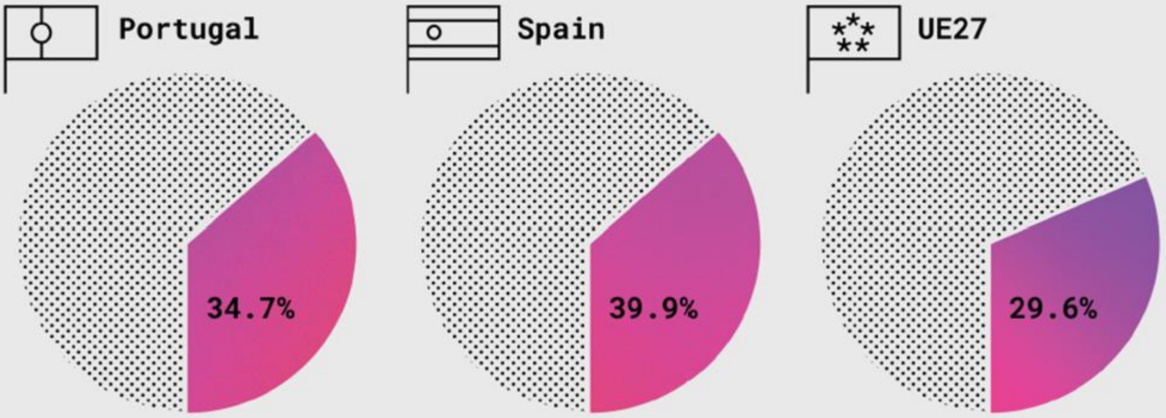
SOURCES: 'EUROSTAT, 20 23'

Funded by the European Union

SOCIAL DETERMINANTS OF HEALTH

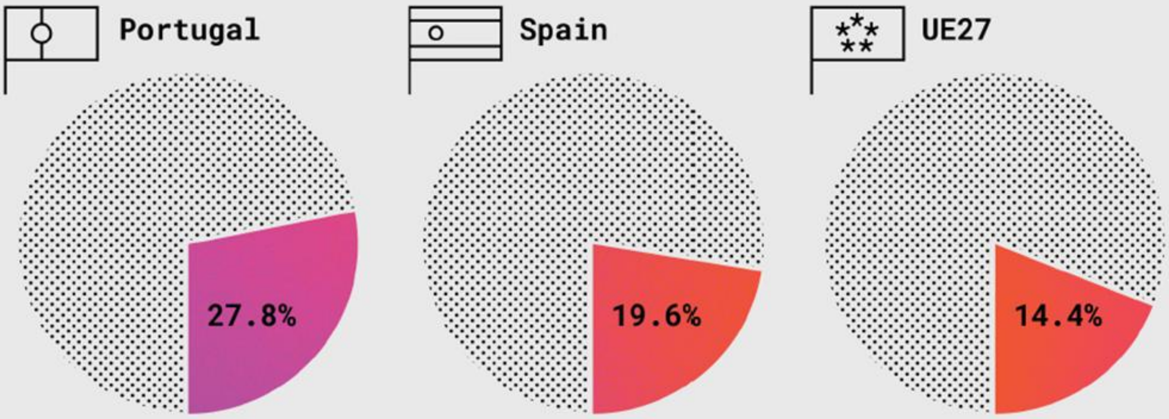
INEQUALITY *(GINI INDEX)*

Gini value (%)



ACCESS TO HEALTH *(OOP = Out-of-Pocket expenses*)*

OOPs as % of current national health expenditure



**OOP ARE DIRECT PAYMENTS MADE BY INDIVIDUALS FOR HEALTHCARE SERVICES NOT COVERED BY THE NATIONAL HEALTH SERVICE, INSURANCE OR OTHER FINANCIAL PROTECTION. HIGH OOP COSTS CAN CREATE FINANCIAL BARRIERS TO ACCESSING HEALTHCARE. THIS IS IMPORTANT FOR AGING POPULATIONS AS THEY OFTEN FACE INCREASED AND LONG-TERM HEALTHCARE NEEDS, POTENTIALLY IMPACTING TIMELY ACCESS TO CARE AND OVERALL WELL-BEING.*

SOURCE: DATA WORLDBANK, 2020,
FOR UE GINI VALUE, EUROSTAT, 2022,
WORLD HEALTH ORGANIZATION (WHO)

Funded by the European Union

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[13] European Federation of Pharmaceutical Industries and Associations, & IQVIA. (2024). Assessing the clinical trial ecosystem in Europe: Final report (October 2024). EFPIA. URL: https://www.efpia.eu/media/oipkatpg/efpia-ct-report-embargoed-221024-final.pdf

[14] World Health Organization: Number of clinical trials by year, country, WHO region and income group (1999-2024). https://www.who.int/observatories/global-observatory-on-health-research-and-development/monitoring/number-of-clinical-trials-by-year-country-who-region-and-income-group

[15] European Federation of Pharmaceutical Industries and Associations, & IQVIA. (2024). Assessing the clinical trial ecosystem in Europe: Final report (October 2024). EFPIA. URL: https://www.efpia.eu/media/oipkatpg/efpia-ct-report-embargoed-221024-final.pdf

[16] Citeline Trialtrove: https://www.citeline.com/en/products-services/clinical/trialtrove

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[17] Associação Portuguesa da Indústria Farmacêutica (APIFARMA). (2025). *Ensaios clínicos em Portugal 2024* (Relatório). APIFARMA.

[18] Bogas, M., Antas, J., Magalhães, C., Revige, M., Guerra, L., Ribeiro, C., Eça, R. C., Nunes, F., Lopes, A., Costa, L., Gonçalves, M., Pedrosa, J., Capela, A., Gregório, T., Dias, P., Alfaro, T., Pais, A., Soares, R., Queirós, A., … & Sousa, N. (2025). *Assessment of competencies of clinical research professionals and proposals to improve clinical research in Portugal*. *Frontiers in Pharmacology*, 16, Article 1578955. https://doi.org/10.3389/fphar.2025.1578955

[19] A Investigação Clínica e a Inovação Biomédica em cancro em Portugal Posição conjunta dos elementos do Policy Group do National Cancer Hub; URL: https://aicib.pt/wp-content/uploads/2023/05/Posicao-conjunta_Cancro.pdf

Pillar 1: Mission-driven Research

Hyperconnected Research

strong networks across:

- GIMM internal research groups: CARE &Discovery
- Hospitals & healthcare professionals
- Patient Associations
- Pharma & biotech industry
- Venture capital & funding agencies

to foster collaborative, cross-disciplinary approaches

Transformative Research

Aim for tangible improvements in target populations
Measure real-world outcomes, not just publications
Align success metrics with patient benefit

Efficient Translational Research

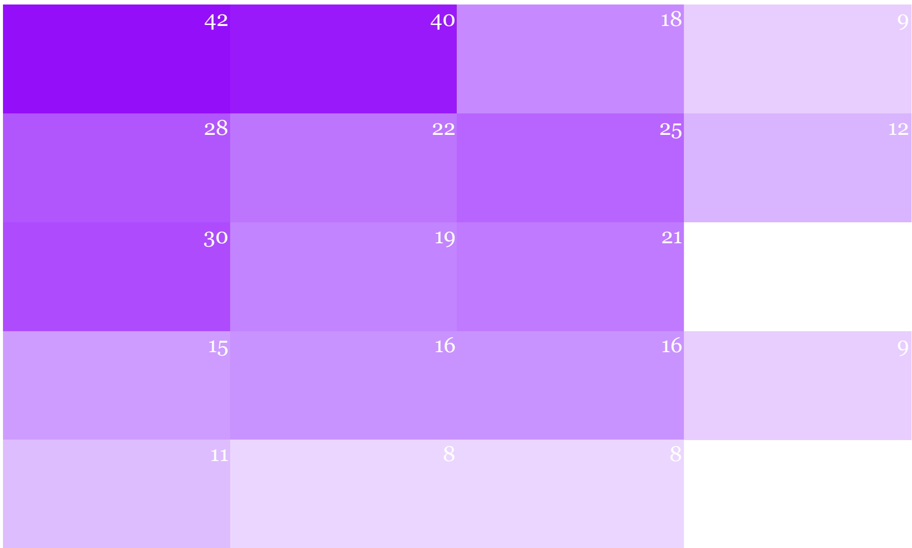
Prioritize innovation with applicability
Define clear Go/No-Go criteria and prioritize “killer experiments” across projects
Focus on measurable short- to mid-term impact
Optimize use of resources and capabilities

Project-based Research

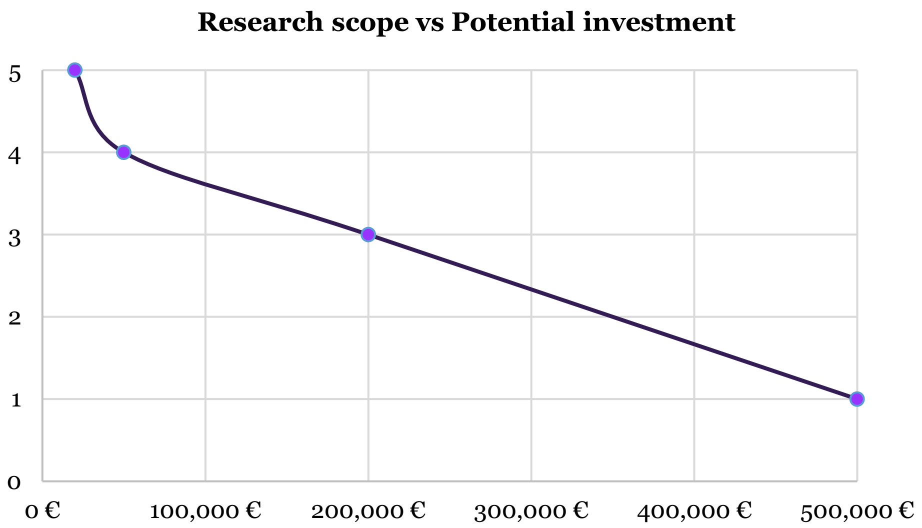
- CARE Flagship projects
- CARE POC projects
- CARE Junior Clinician projects
- CARE Strategic projects

Translational Labs

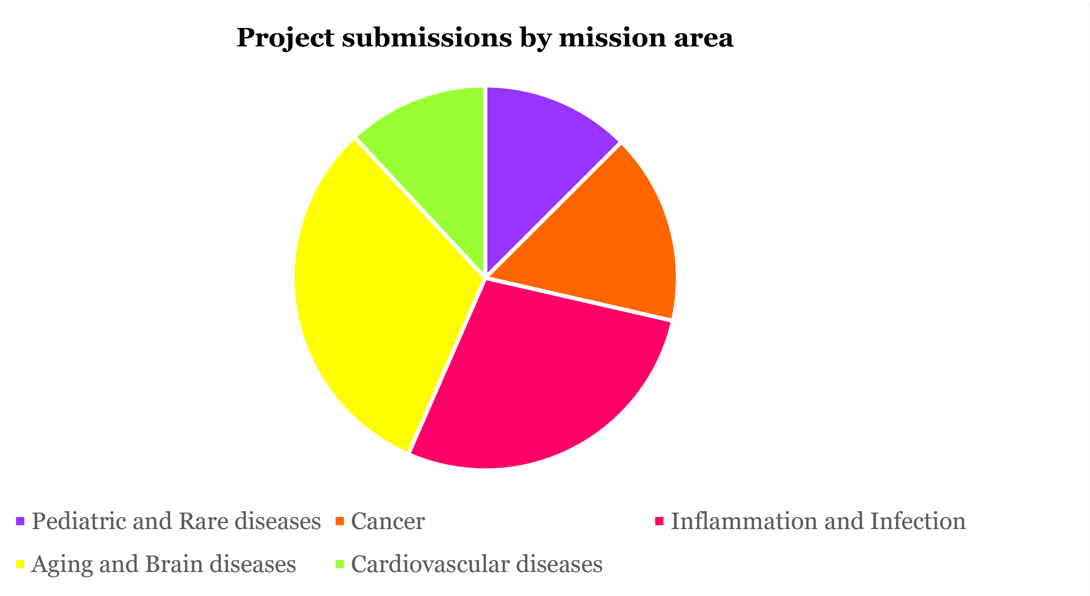
- Advanced Breast Cancer
- Oncology
- Microbiome in health & disease
- Brain cancer dynamics & therapy



42	40	18	9
28	22	25	12
30	19	21	
15	16	16	9
11	8	8	



Research scope vs Potential investment



Project submissions by mission area

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[20] https://care.gimm.pt/gimm-open-calls/







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[21] https://gimm.pt/gimm-festival-2025/

Do you know what this is?

Then your health still has stories to tell

Participate in Mapa da Idade, *a scientific study that values your experience.*

If you are between the ages of 40 and 80, GIMM needs you. Participate in Mapa da Idade, a scientific study that uses advanced methods to validate the concept of the biological clock in the Portuguese population and compare biological age with chronological age. Help us identify health risks in the Portuguese population. Participation is free, and breakfast is included.

Your morning with us:

1. Reception & Ethics
A personalized welcome and clear explanation of each step. We guarantee the full protection of your data.

2. Express physicial check-up
Quick and precise measurements of blood pressure, hand strength, and body composition to assess your vitality.

3. Lab Sample Collection
Quick, safe, and minimally invasive blood and urine sample collection.

4. Moment of Pause
After sample collection, we offer a nutritious breakfast and assist you in completing a questionnaire about your lifestyle and clinical history.

Learn more:

This study is for people aged between 40 and 80.

Questions: mapadaidade@gimm.pt
Website: gimm.pt

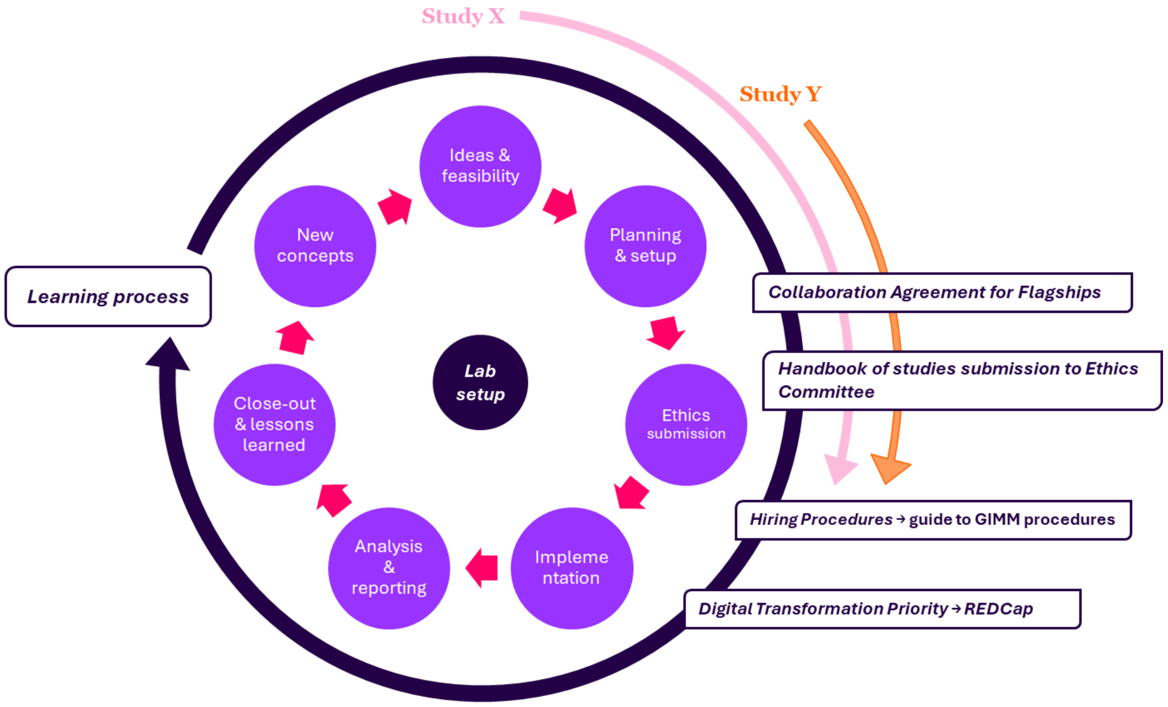
Partner

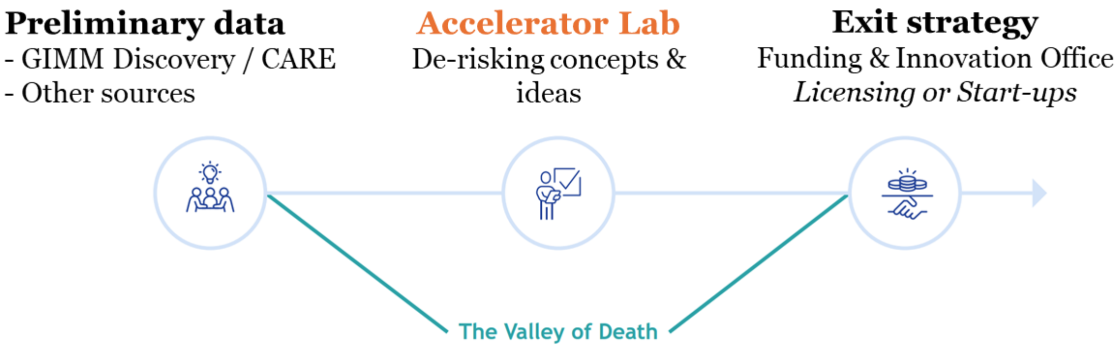
Pillar 2: Training ad Mentoring

Funded by the European Union
REPÚBLICA PORTUGUESA fct Fundação para a Ciência e a Tecnologia Jerónimo Martins Arica CAML UNIDADE LOCAL DE SAÚDE SANTA MARIA Faculdade de Medicina GIMM Vall d'Hebron Research Institute GIMM CARE

Funded by the European Union

Pillar 3: Clinical Research Support


Study X
Study Y
Ideas & feasibility
Planning & setup
Ethics submission
Impleme ntation
Analysis & reporting
Close-out & lessons learned
New concepts
Lab setup
Learning process
Collaboration Agreement for Flagships
Handbook of studies submission to Ethics Committee
Hiring Procedures → guide to GIMM procedures
Digital Transformation Priority → REDCap

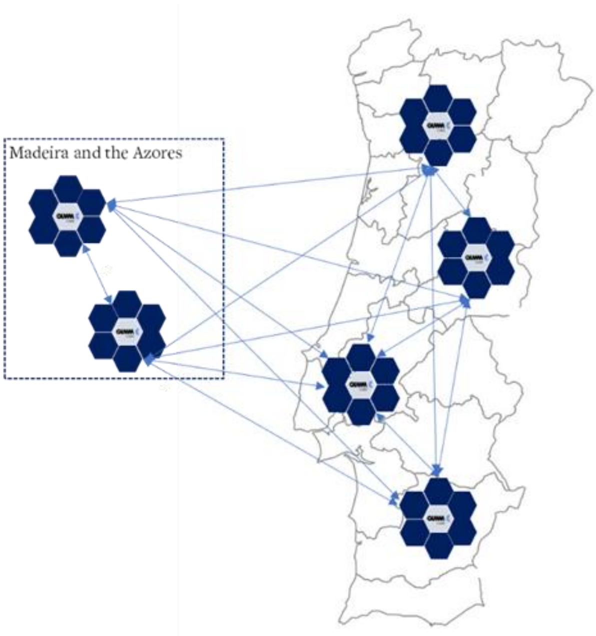


Preliminary data
- GIMM Discovery / CARE
- Other sources

Accelerator Lab
De-risking concepts & ideas

Exit strategy
Funding & Innovation Office
Licensing or Start-ups

The Valley of Death



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[22] https://zenodo.org/records/18352446

Pillar 4: Next-generation Biobank

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[23] https://aicib.pt/wp-content/uploads/2026/02/Green-Paper-Biobancos-1.pdf

Funded by the European Union
Vall d'Hebron Research Institute
REPÚBLICA PORTUGUESA
Arica
Jerónimo Martins
fct Fundação para a Ciência e a Tecnologia

U Lisboa | M Faculdade de Medicina
CAML Centro Académico de Medicina de Lisboa
UNIDADE LOCAL DE SAÚDE SANTA MARIA
"la Caixa" Foundation
FUNDAÇÃO CALOUSTE GULBENKIAN

U LISBOA | UNIVERSIDADE DE LISBOA
UNIDADE LOCAL DE SAÚDE ALENTEJO CENTRAL
UNIDADE LOCAL DE SAÚDE AMADORA / SINTRA
HOSPITAL DA LUZ
cuf
Champalimaud Foundation

DGS Direção-Geral da Saúde
AICIB Agência de Investigação Clínica e Inovação Biomédica
NCH PT
FORUM SAÚDE XXI Health for all in a sustainable world
eatris
EU-LIFE
esa

AGÊNCIA ESPACIAL PORTUGUESA
ACREDITAR Associação de Pais e Amigos de Crianças com Cancro
aeccer
evita
Amigas do Peito
LIGA PORTUGUESA CONTRA O CANCRO
europacolon portugal

AcceliBio
Fundação José Luiz Setúbal
Kochard Foundation
Universidade de Évora
Bial
JOAQUIM CHAVES SAÚDE DESDE 1959
PORDATA

GILEAD
AMGEN
Instituto Ramón y Cajal de Investigación Sanitaria IRYCIS
IRB Barcelona
UNIVERSITY OF BIRMINGHAM
ICS INSTITUTO DE CIÊNCIAS SOCIAIS

OEIRAS VALLEY PORTUGAL
LISBOA CÂMARA MUNICIPAL
MOAI Stepping stone to knowledge


GIMM CARE
Science Rounds
2nd Tuesday of every month | 12h30
1 Clinician, 1 Researcher
2 Perspect... collaborati...

Advanced Data Analysis	Governance, Data Management & Open Science	Research Computing Solutions	Enterprise Solutions	Infrastructure & Information Security	Service Desk
Bioinformatics, Data Analysis, RNA Sequencing, Metagenomics, Transcriptomics, Statistical Data Analysis, Community Tools, Trainings & Workshops	IT Governance and processes, Grant Management, General Data Management, Open Sciences, Data Policies, Bibliometrics, Scientific Services, Scientific Applications	Clinical and Research Data Management, Research Data Storage, High Performance Computing, Monitoring	Management of new Solutions Projects, Analysts, Business Requirements, Project Delivery, Project Reporting, Technical Solution Owners, Business Partners	Datacenter Management, Servers, Hardware, Networking, Monitoring, Cybersecurity and Compliance	Identity & Access Management, Endpoints & Workstations, Hardware, Networking, VPN, Printing, Software, Applications, Storage, Data Backups

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Funded by the European Union

Begoña Benito, MD PhD (Spain) *XXX*

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[25] https://acreditar.org.pt/
[26] https://evitacancro.org/
[27] https://amigasdopeito.pt/
[28] https://apccerebro.pt/
[29] https://www.europacolon.pt/home

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GIMM CARE is open to collaboration requests from any interested parties, particularly healthcare professionals, patient associations or other national and international healthcare stakeholders.

The best way to connect with GIMM CARE collaborators is via the **CARE mailbox** **care@gimm.pt.** Let us know i) which research topics you are interested in, ii) what you are looking for (advice, tools, facilities, samples) and/or iii) your expertise and what you would like to offer, and GIMM CARE team will facilitate the connections. Please also mention your affiliation(s) (e.g. which hospital and service, which institute etc).