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From Subjects to Partners: Rethinking Research Methodologies through Citizen Science[1]

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Summary

The article will first introduce a general definition of Citizen Science (section 1), followed by an excursion of its foundations and of the different understandings and ways of applying it, with examples drawn from diverse research and policy areas (section 2). It will then focus more closely on the field of health and the environment (section 3), including occupational medicine (subsection 3.1), community response to environmental risks (section 3.2), biomonitoring (sub-section 3.3), and human biomonitoring (subsection 3.4). Section 4 will address some of the advantages (section 4.1) and challenges (section 4.2) of adopting CS in research and policy. Finally, section 5 will trace the legislative and normative background of participatory approaches and point to the challenges ahead.

1. Introduction

This article does not aim to provide a systematic review of Citizen Science (CS) practices and applications, nor is it primarily focused on biomonitoring. It describes the basics of CS, identifies its precursors, and provides several examples of its applications in various research areas, including biomonitoring. The primary objective of this work is to demonstrate the potential of working in a multi-, inter- and trans-disciplinary mode, highlighting both its advantages and challenges, while also considering socio-political contexts and the normative framework.

Overall, citizen science refers to the involvement of members of the general public, laypeople, volunteers, non-credential researchers, and non-professional scientists in scientific research activities through a range of participatory approaches. Such actors may be individual or collective, such as NGOs, activist groups, pressure groups, private businesses, and public administrators. Experiences generally grouped under the umbrella term of Citizen Science (CS) have been growing exponentially over the last few decades, covering a wide range of diverse topics and research areas. Though the term is relatively recent [1, 2], the same cannot be said for the ideas at its roots. Indeed, some similar practices date back decades and even centuries, being considered innovative and even daring for the times they were introduced.

As a side note, it is worth recalling that, as Kaiser [3] pointed out, the term "scientist" with its current meaning was introduced less than two centuries ago.

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This marked the shift from the (amateur) natural philosopher of the Scientific Revolution to a professional scientist with recognized status, defined roles, and specific tasks. Additionally, disciplines as we know them today were established only in the 19th and 20th centuries and have rapidly expanded since then, including the creation of subdisciplines that led to increasing specialization, university departments, faculties, sectors, and units [3].

The term Citizen Science was independently introduced in the mid-1990s by two scholars from different backgrounds: Alan Irwin, a sociologist, [1] and Rick Bonney, a wildlife expert. Their focus differed: Irwin emphasized the level and quality of engagement and the ownership of knowledge, while Bonney concentrated on the volume and speed of data collection. Although the label CS is quite new, the activities it includes are not; some examples date back decades and even centuries. These activities include fossil or plant gatherers who donated their finds, collections, drawings, and catalogs to museums or scientific societies. Additionally, in a somewhat different category, are craftsmen who solved technical and scientific problems that had stumped renowned scientists, or natural philosophers, of their time. For instance, John Harrison, with his precise clocks, developed a reliable method for measuring longitude—a complex problem that haunted the best minds of the 18th century and caused significant loss of life and economic damage [4].

Among collective experiences, a notable one is the Nature's Calendar, a British phenology project that started in 1736 when Robert Marsham began recording in his diary "indications of spring" on his family estate. The project now involves about 40,000 people observing 67 spring events and 24 autumn events related to nature across the UK [5]. Similar initiatives are countless, from volunteers tagging monarch butterflies to track migrations, to sailors contributing to oceanographic research, and fishermen providing input to establish fishing quotas.

2. FOUNDATIONS AND TYPOLOGIES OF CITIZEN SCIENCE

The ideas associated with the term CS have been accumulated over time under various labels, such as action research, participatory action research, community-engaged research, and community-based participatory research (CBPR). They also align with the concept of "extended peer community" introduced within the framework of Post-Normal Science (PNS) [6], which I will revisit.

In any case, the term CS quickly became popular and was soon accepted by many groups, even though its understanding and ways of application often vary significantly. Additionally, a terminological debate soon arose, giving rise to a vast and growing body of literature. The term "citizen," for example, may sound exclusive or non-inclusive, as it omits those who do not hold official citizen status. And is there such a thing as a "general public"? "Lay people" is a too broad and reductive term, as is "volunteers," among others. Expressions like "community science" and "civic science" are gaining prominence, along with related terms such as "community scientists" and "civic scientists," which are sometimes intended to include both professionals and non-professionals—focusing on interest and commitment rather than on roles or credentials. Similar dilemmas exist around defining knowledge that cannot be fully expressed in scientific terms but is still relevant and valid for understanding and addressing certain issues: lay knowledge, local knowledge, situated knowledge, lived knowledge, experiential knowledge, lived experience, and so on. Nonetheless, the terms citizen science/scientists remain the most widely used in the literature, sometimes accompanied by an explanatory note.

Yet, far from pointing to a very specific, unambiguously defined type of activity, CS is an umbrella term that encompasses a wide range of understandings. Especially since the 2010s, proposals for classifications, typologies, frameworks, and mapping have multiplied in an effort to provide clear yet nuanced distinctions. However, this has also inevitably led to some disagreement and confusion. For example, in 2015, ECSA (European Citizen Science Association) developed and shared its Ten Principles of Citizen Science [7], translating them into all official EU languages, as well as other languages spoken across the 27 EU countries and many languages worldwide. Yet, many believed these principles were insufficient for distinguishing what qualifies as citizen science and what does not. Around ten years later, a group of 19 researchers aimed to address some of these gaps and ambiguities in defining citizen science practices [8].

A recent study identified 13 types addressing various aspects of citizen science [9]. Some of these types are more popular and widely adopted than others [10]. Here is a simplified version based on the previously mentioned types, with the level of engagement of non-professionals as its main criterion: a) crowdsourcing (or contributive) involves laypeople acting as data collectors, an unpaid workforce performing tasks designed by professionals; b) co-created design signifies full collaboration between lay and professional scientists; c) extreme (or autonomous) citizen science includes initiatives led by lay participants, with scientists possibly serving as advisors or consultants. The third type is somewhat the reverse of the first, with professional scientists being hired as service providers, likely for payment. This is a simplified typology, and many intermediate forms could exist. Crowdfunding is related, although not exclusive to citizen science projects. It involves collecting money to fund projects that are not, or not sufficiently, sponsored by traditional sources. Participation, engagement, and involvement are terms often used in the literature, sometimes interchangeably or arranged on a scale from lower to higher levels of involvement [11].

Evidently, different modes involve significant differences in power dynamics and how leadership is attributed, especially regarding framing the research question, choosing the research design and methods for data collection and analysis, and ownership and dissemination of results, including their use in policy processes. The recognition of power as a crucial issue in participatory experiences was highlighted by Sherry Arnstein, somewhat ahead of her time, in the context of urban planning. In her widely cited 1969 paper, she proposed a ladder with eight rungs, grouped under the three categories of "non participation, tokenism and citizen power" [12].

Not surprisingly, most experiences so far fall into the first category, crowdsourcing, regardless of the research area. Their rapid growth is mainly due to the spread of digital media. Smartphones, tablets, inexpensive sensors, open-source software and platforms, high-speed internet, and powerful computers have all expanded possibilities for data collection, access, management, storage, and sharing. A well-known example is the crowdsourced astronomy project Galaxy Zoo, which focuses on classifying the shapes of large numbers of galaxies [13]. It gained major visibility early on, starting in 2007, thanks in part to extensive coverage by the mainstream press. Overall, projects related to ecology and the environment are most common. Still, more examples are emerging across diverse research fields: archaeological exploration, anthropology, disaster studies, history, sociolinguistics, space and astronomy, technological innovation, and increasingly, health, epidemiology, and biomonitoring—areas I will now explore in more detail.

3. CITIZEN SCIENCE IN THE ENVIRONMENT AND HEALTH

This section will focus on Citizen Science initiatives which relate to the fields of health and the environment including some innovative experiences which preceded the emergence of the CS vocabulary.

3.1. Occupational Medicine

Aspirations for the "democratization of medicine"—including a renewed doctor-patient relationship and increased attention to environmental stressors—have existed for decades, coming from both civil society and the medical community itself. In Italy during the late 1960s and 1970s, these ideas led to several noteworthy innovative practices, especially in occupational medicine. During a time of student protests and class struggles, numerous initiatives emerged that could be called, in today's terms, citizen science. "Citizens" in this context were mainly workers employed in large factories in the metallurgical and chemical sectors. Alongside medical and other healthcare professionals from various backgrounds, they promoted new ways of understanding and addressing the impact of the work environment on people's health, rejecting monetary compensation for exposure to toxic and other risky agents and instead emphasizing safety, prevention, anticipation, and care.

The experiences of the "homogeneous groups" – groups of employees sharing the same working environment and consequently being exposed to similar risks - were genuinely participatory and trans-disciplinary, integrating the contributions of experts from different disciplines (through measurements, tests, etc.) with knowledge ensuing from the lived experience of the workers. In the typology presented above, such experiences would fit into the category "co-created", or even "extreme" Citizen Science. This innovative form of full collaboration between workers and technicians was possible thanks to the individual commitment of many (mostly young) medical professionals, as well as the support of some established academics and prestigious institutions such as the Clinica del Lavoro Luigi Devoto in Milan, in a new season of legislative reforms promoting and expanding civil rights [14-21].

3.2. Communities at Risk and Patient Activist

Ideas and initiatives related to the safety of the working environment gradually expanded to encompass the broader environment. This shift moved the research focus from specific workplace settings to entire communities, where residents often organized or led their own investigations to detect toxic elements after experiencing unexplained symptoms. The Love Canal case, a residential area near Niagara Falls in New York state, is perhaps the most well-known example of what the main (female) protagonist called "housewives epidemiology" [22] (see also [23]). Popular epidemiology is also a commonly used term for these kinds of experiences, [24].

Similarly, it was due to the persistence of advocates for patients who had been undiagnosed and untreated for decades that the cause of what is now called Lyme disease was finally discovered, and treatment became available in the early 1980s [25]. Another well-known case from before the CS nomenclature was established is summarized by Epstein in the abstract of his 1995 article with these words: "In an unusual instance of lay participation in biomedical research, U.S. AIDS treatment activists have established themselves as credible contributors to the knowledge-building process, leading to changes in the epistemic practices of biomedical research" [26] (p. 408). The author further adds: "This surprising result is, of course, at odds with the popular idea of science as a fairly autonomous field with high barriers to entry" [26] (p. 409).

Over the years, associations of patients or undiagnosed, untreated individuals have proliferated, building their agendas on different philosophies and strategies, but all sharing the goal of giving people with similar conditions the opportunity to share information and experiences and provide mutual support. One notable example is PatientsLikeMe [27], created in 2005 by the two men who became citizen scientists after their brother had been diagnosed with ALS (amyotrophic lateral sclerosis) in 1998. In 2011, the digital health platform began to include communities of patients with other conditions, and as of 2025, it has more than 850,000 members across over 2,800 conditions. PatientsLikeMe works in partnership with various public and private institutions and commercial businesses, including pharmaceutical companies.

However, in many circles, there is a widespread skepticism and even mistrust toward the research establishment. Suspicion has been fueled by cases such as that of Henrietta Lacks', which was brought to public attention by Rebecca Skloot. From her highly publicized 2010 book [28], large audiences learned that significant benefits—economic and otherwise—had been gained from the continuous use of the "immortalized cell line" of a poor African-American woman who died of cervical cancer in 1951 in Baltimore, at the only hospital that would admit her during racial segregation. Neither she nor her family were informed, and it was only in the mid-1970s that her relatives discovered what had happened and began to claim their rights to information, privacy, and economic profits, sparking a broad debate and several posthumous recognitions of Henrietta's unknowing contribution to scientific research.

3.3. Biomonitoring

In biomonitoring research, CS practices appear to be gaining rapid popularity and broader acceptance as they are no longer solely used by pioneers but also by mainstream researchers. Crowdsourcing is the most common approach, with non-professionals guided by scientists to use various methods for detecting and measuring pollution and ecotoxicity from many agents, both natural and artificial, such as chemicals, glass fibers, metals and metalloids, microplastics, oil, pesticides, PFAS, plasticizers, and substitutes. Nearly any type of element or environment has been investigated when the proper tools are available and conditions permit: air, fresh water, lagoons, seas, oceans, coastal zones, soil, sediments, food, plants, animals (vertebrates and invertebrates), biodiversity, and the human body— the last, which I will discuss separately below. So far, no geographic area has remained unexplored, including the most remote or hard-to-reach places, like the Russian Arctic [29] or the Canadian permafrost zone [30]. In the latter case, a community-based participatory research (CBPR) approach for health impact assessment related to development plans was chosen, involving indigenous communities more than in crowdsourcing. However, as explained further in section 4.1, many barriers still exist in these efforts.

A quite different and somewhat paradoxical example – given the high environmental impact of the transport means – consists of observations provided by cruise ship passengers, including those in the Arctic and Antarctica. These passengers collect observations (pictures, videos, notes) on animals, plants, and natural phenomena such as aurora borealis and australis using mobile applications supported by artificial intelligence that helps with recognition and classification. These contributive practices, along with others involving birdwatchers, hikers, hunters, mushroom collectors, fishermen, and more, are often promoted by educational institutions or scientific societies.

3.4. Human Biomonitoring

Due to high expectations regarding the results and impact of HBM research, there is significant investment in securing broad participation of potential subjects in local, national, and international HBM projects and programs. People's knowledge, perceptions, and attitudes are examined through surveys or focus groups to help develop strategies for facilitating recruitment [32, 34, 35, 37].

The importance of informing research subjects is universally recognized, but a one-way communication approach still prevails in practice despite acknowledgment of the greater effectiveness of a two-way method [31-35]. Building multidisciplinary networks is recommended, including a wide range of expertise related to health—such as physicians, chemists, biochemists, biologists, toxicologists—and from social sciences and humanities, like social psychology, sociology, history, ethics, and media studies [32, 33, 35]. Even so, the preference for top-down strategies appears to dominate, viewing potential study participants as subjects to be informed and educated not only about the technical aspects of HBM research but also about the value of bio-surveillance HBM programs for individual and societal well-being [33]. When suggesting strategies, recommendations, roadmaps, and toolkits, authors do acknowledge some lessons from risk communication literature but rarely report firsthand initiatives [34, 36]. Currently, in HBM research and practice, the situation differs significantly from that of occupational medicine practices in the late 1960s and 1970s, described in section 3.1 [14-21].

Genuinely participatory research entailing equal partnership between scientists and non-professionals as in co-created projects is still in its infancy. It has to be acknowledged, as it will be detailed later, that the challenges are significant and require considerate and careful planning. Big projects such as the recently completed HBM4EU [38] or the ongoing PARC [39] are already so challenging in coordination tasks [40] to appear an unlikely place for large scale citizen science experimentation, even if it is acknowledged as worth pursuing [36, 41].

Smaller projects appear more suitable for testing and evaluating the feasibility of full partnerships between professional and non-professional scientists in co-created research initiatives. For example, the CitieS-Health project [42-45] also offered a toolkit to facilitate similar practices [46]. The newly initiated project, One Health Citizen Science [47], is applying a similar model across various Italian sites, including Valle del Serchio, which was already part of the previous CitieS-Health project. The smaller scale of these projects also enables experimentation with inter- and trans-disciplinary collaborations aimed at genuinely integrating diverse perspectives (rather than merely combining them), whether disciplinary or not. This approach should ideally lead to framing HBM and bio-surveillance broadly, with increased focus on sensitive socio-ethical issues, including "societal risk," which has received limited or insufficiently sophisticated attention so far. I will briefly mention some of the issues raised by scholars from the social studies of science tradition.

Extensive bio-surveillance can have negative effects on individual privacy and enable harmful uses of control and restrictions on personal freedoms. Additionally, when people are turned into chemical sensors for environmental issues, the line between body, self, and environment becomes blurred, making personal experience less unique. Both individual and collective identities may be redefined in techno-scientific terms, leading to new "bio" social phenomena such as biological citizenship, bio-sociality, bio-activism, and biomedicalization, possibly shifting the responsibility for risk exposure and preventive measures [48-51]. While not all these developments may be negative, they still require foresight from an "extended peer community," including not just scientific experts but also various social actors. In fact, when viewed in its full complexity, HBM is just one of many current problems with policy implications that can be described by the post-normal science (PNS) principle: "uncertain facts, values in dispute, high stakes, and urgent decisions" [6].

4. ADVANTAGES AND CHALLENGES OF CITIZEN SCIENCE

CS projects and programs share some advantages and challenges with more traditional types, occasionally exaggerated, while some are unique to that specific approach. Nearly all papers on the topic include a list of benefits and drawbacks, either theoretically defined or practically observed. Some refer to the research team, others to the external environment, and some address both. Below, I will briefly list the most common ones, highlighting those specific to health research, many of which are summarized in [52-53].

4.1. Advantages

As already mentioned, the possibility of acquiring more data quickly often influences the decision to include non-professionals in research activities. While this is generally true for the contributory type of CS, it is not necessarily the case with other CS modes, where the process can actually be slowed down. The perspectives offered by "lay people" and their contributions, which provide valuable but not strictly scientific knowledge, are often more appreciated in more inclusive initiatives that are open to the possibility of even redefining research questions and procedures. In such cases, reciprocal learning is emphasized rather than one-way instruction. Other often-cited benefits include the lay participants' chance to learn more about the issues being studied, improve their scientific literacy by familiarizing themselves with research procedures, and even change their behaviour based on the new awareness and knowledge they gain.

People often assume there is increased trust in scientists and scientific research, but this trust is not guaranteed and depends on several factors. One of the most important factors is the relationship built between professionals and citizen scientists. For instance, lack of transparency or violations of agreements about sharing results or using data and findings (research versus commercial use) can weaken or even ruin trust—not only in a specific group of researchers but in the scientific community as a whole. This is especially true in environmental and health research, particularly concerning BM and HBM (whether CS or not), where there is a strong emphasis on using the knowledge gained to implement appropriate measures for regulation, prevention, remediation, management, and governance.

4.2. Challenges

The recruitment of research subjects involves many well-known challenges, not only technical (e.g., sample validity, data anonymization, etc.) but also other types, especially when it comes to HBM, which requires acquiring body fluids and tissues, inevitably raising sensitive socio-ethical issues [48], including privacy concerns, reporting individual and community exposure, and more. Regarding report-back in personal exposure studies, the debate remains open, and different approaches exist. According to a study based on in-depth interviews with various stakeholders and a review of relevant literature, new forms of community-based research ethics and participatory scientific practice are emerging [54].

In CS health projects, both technical and ethical issues can become more complex because non-professionals are not just research subjects; they often become partners to some extent and have their say. This includes decisions on platforms (opensource vs. proprietary), use and dissemination of results, which challenges the power balance within the research team. This is a key issue, as previously discussed in section 2. Delegating some of these concerns to ethical committees isn't easy, especially in international research projects, since rules and procedures vary greatly between countries and can often be confusing, conflicting, or even contradictory within the same country [43] (see also [40]). Reaching preliminary agreements takes time—a valuable resource in research—and some issues may remain unresolved if disagreements occur, causing internal conflicts and fatigue. Additional challenges come from the diversity of traditions, cultures, and jargon, not only across disciplines but also across different fields of study.

In some cases, differences may appear insurmountable, such as between Indigenous communities and research or government institutions, whose worldviews inevitably clash from the very beginning, starting with the way they conceptualize problems. For example, this is evident in the impact assessment of development plans, which the former views holistically, while the latter sees as separate components to be studied by different disciplines and managed with various governance strategies [30] (p. 449). Trust, which is essential for success, is not automatically given; it must be patiently built through openness, clarity, and fairness, as suspicion of sham participation [37] can arise both internally and externally. Additionally, and rarely mentioned in the literature, there may be cases where internal boycotts occur—where individuals or groups prefer the failure of the participatory project over its success due to personal or collective hidden agendas.

CS projects of all different types still face significant hesitation in the academic setting, especially if they are large, particularly innovative, or cause concern due to potential objections from important stakeholders, especially research sponsors. Doubts about the quality of data and the proper assessment of methods and results are often raised in many areas, and acceptance by regulatory agencies and decision makers is not always guaranteed [52].

5. Conclusion and Way Forwards

The origins of CS in health and environmental research trace back to times of political struggles for workers' and citizens' rights, when such issues were often not a priority on institutional agendas [14-22]. Emerging during periods of social mobilization and calls for justice, these early efforts anticipated the participatory shift that later transformed the relationship between science, policy, and society. Over the following decades, increased awareness of the crisis facing traditional institutions—and ultimately, democracy itself—prompted calls for reform across various areas, leading to a re-evaluation of science's role in society and the rights and duties of citizens.

Today, many conventions, declarations, and policy frameworks recognize citizens' rights not only to access information but also to actively participate in decisions and processes that affect their lives. Research and political institutions have gradually adjusted their goals and strategies to align with these principles. In the European Union, for example, the so-called Seveso Directive was the first to introduce the obligation to inform the public about risks, specifically major-accident hazards. Later revisions expanded this principle by including participatory mechanisms in risk governance [55]. Similar commitments appear in the REACH Regulation [56], which in point (117) of its preamble affirms citizens' rights to information, justice, and participation in decision-making.

Regarding research policies, a significant change for CS and similar activities happened with the Framework Programme Horizon 2020, which ran from 2014 to 2020, following the European Commission Green Paper on CS in 2013. Its goal was "to foster the interaction between the Citizen Science stakeholders and the EU policy officers" [57] (p. 8). The trend continues with the current Framework Programme Horizon Europe, covering 2021-2027, which promotes citizens' participation in various scientific fields. Additionally, the European Commission established the Competence Centre on Participatory and Deliberative Democracy, [58] whose main goal is to support the development of socially robust policies through citizen engagement.

Yet, the future of these participatory goals remains uncertain. In a time marked by renewed attacks on both science and democracy, the institutionalization of CS cannot be assumed. Efforts to revive outdated models are unlikely to address the challenges we face today. Instead, as Donna Haraway [59] suggests, we may need to "stay with the trouble": to accept the messy, complex realities of coexistence. As she writes, "Staying with the trouble requires making odd kin; that is, we require each other in unexpected collaborations and combinations, in hot compost piles. We become with each other or not at all. … Learning to stay with the trouble of living and dying together on a damaged earth will prove more conducive to the kind of thinking that would provide the means to building more livable futures." [59] (pp. 3 and 4).

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