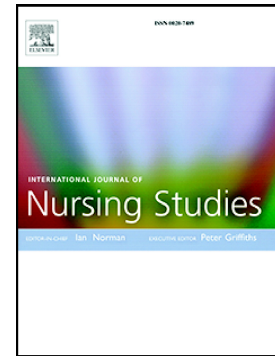


Journal Pre-proof

Community-driven research: Exploring the potential of citizen science in nursing

Giulia Villa, Debora Rosa, Ilaria Marcomini, Andrea Poliani, Pier Raffaele Spena, Roberto Buccione, Duilio F. Manara, Maya Fedeli



PII: S0020-7489(25)00134-8

DOI: <https://doi.org/10.1016/j.ijnurstu.2025.105125>

Reference: NS 105125

To appear in:

Received date: 26 June 2024

Revised date: 21 May 2025

Accepted date: 22 May 2025

Please cite this article as: G. Villa, D. Rosa, I. Marcomini, et al., Community-driven research: Exploring the potential of citizen science in nursing, (2024), <https://doi.org/10.1016/j.ijnurstu.2025.105125>

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TITLE

Community-Driven Research: Exploring the Potential of Citizen Science in Nursing

Authors

Giulia Villa^{1*}, Debora Rosa¹, Ilaria Marcomini¹, Andrea Poliani¹, Pier Raffaele Spena², Roberto Buccione³, Duilio F. Manara¹, Maya Fedeli³

Affiliations

¹ Center for Nursing Research and Innovation, Faculty of Medicine and Surgery, Vita-Salute San Raffaele University, 20132 Milan, Italy

² Federazione delle Associazioni Incontinenti e Stomizzati, Milan, Italy

³ Research Policy, Research Development Area, Vita-Salute San Raffaele University, Milan, Italy

Author position		
1	Author	Giulia Villa Corresponding author
	Affiliation	Center for Nursing Research and Innovation, Faculty of Medicine and Surgery, Vita-Salute San Raffaele University, 20132 Milan, Italy
	Contact	Address: Center for Nursing Research and Innovation – CeNRI Vita-Salute San Raffaele University, Via Olgettina, 58 – 20132 Milan, Italy e-mail: villa.giulia@hsr.it Telephone: 02 91751 779
2	Author	Debora Rosa
	Affiliation	Center for Nursing Research and Innovation, Faculty of Medicine and Surgery, Vita-Salute San Raffaele University, 20132 Milan, Italy
	Contact	e-mail: rosa.debora@univr.it
3	Author	Ilaria Marcomini
	Affiliation	Center for Nursing Research and Innovation, Faculty of Medicine and Surgery, Vita-Salute San Raffaele University, 20132 Milan, Italy
	Contact	e-mail: marcomini.ilaria@univr.it
4	Author	Andrea Poliani
	Affiliation	Center for Nursing Research and Innovation, Faculty of Medicine and Surgery, Vita-Salute San Raffaele University, 20132 Milan, Italy
	Contact	e-mail: poliani.andrea@univr.it
5	Author	Pier Raffaele Spena
	Affiliation	Federazione delle Associazioni Incontinenti e Stomizzati, Milan
	Contact	e-mail: p.spena@faisitalia.it
6	Author	Roberto Buccione
	Affiliation	Research Policy, Research Development Area, Vita-Salute San Raffaele University, Milan
	Contact	e-mail: buccione.roberto@hsr.it
7	Author	Duilio F. Manara
	Affiliation	Center for Nursing Research and Innovation, Faculty of Medicine and Surgery, Vita-Salute San Raffaele University, 20132 Milan, Italy
	Contact	e-mail: manara.duilio@hsr.it
8	Author	Maya Fedeli
	Affiliation	Research Policy, Research Development Area, Vita-Salute San Raffaele University, Milan
	Contact	e-mail: fedeli.maya@univr.it

CRedit author contribution statement:

Buccione Roberto: Writing - Review & Editing

Fedeli Maya: Conceptualization, Resources, Writing - Original Draft, Visualization

Manara Duilio F.: Writing - Review & Editing, Supervision

Marcomini Ilaria: Writing - Original Draft,

Poliani Andrea: Writing - Original Draft,

Rosa Debora: Writing - Original Draft,

Spena Pier Raffaele: Conceptualization, Writing - Review & Editing, Supervision

Villa Giulia: Conceptualization, Resources, Writing - Original Draft, Visualization

Abstract

Citizen science, part of participatory science, emerged in the mid-1990s and involves volunteer non-professional scientists in developing and conducting research. The direct involvement of citizens can improve research outcomes, increase trust in science, and ensure that research and innovation align with societal values, expectations, and needs. Patients' and caregivers' participation in research can significantly enhance treatment adherence, self-care skills, adaptation to new living conditions, conscious use of healthcare systems, and reduction of side effects. In this article, we explore the concept of Citizen Science as applied to the nursing field and serves as an informed guide for nurses who wish to test or adopt this new approach to research: we summarize different types of citizen science approaches, define key principles for good practice, and outline the characteristics that a Citizen Science research project should have. We also illustrate how Citizen Science approaches can be incorporated into nursing research and highlight important factors to consider to ensure the effectiveness, reliability, and inclusiveness of Citizen Science projects.

The implementation of this methodology offers new perspectives to help nurses lead and contribute to initiatives that generate meaningful evidence and promote a collaborative, patient-centered approach to healthcare research. Introducing this community-driven research approach to nursing research could help create and guarantee value-based healthcare because of the intervention of patients' and caregivers' opinions and outcomes. It has the potential to make a significant contribution to the field of nursing by involving patients in research areas as co-authors and designers of research projects.

Keywords: Citizen Science, Nursing, Open Science, Public Engagement, Research Inclusion

What is already known

- Citizen Science is experiencing growth and increasing appreciation in the areas of biomedicine, health equity, and public health research, as well as other fields and disciplines such as astronomy and environmental sciences.
- There is a significant research gap, and also a gap in nursing research practice, with a marked absence of literature on the application of Citizen Science methodologies to nursing research.

What this paper adds

- Citizen Science is an innovative methodological approach also valid for nursing research.
- The potential relevance of Citizen Science for inclusion in nursing education curricula, such as in research and community health coursework at Master's and PhD levels, is highlighted.

INTRODUCTION

Citizen Science and Open Science, Responsible Research and Innovation, and Public Engagement

1. Citizen Science can be defined as *“the voluntary participation of non-professional scientists in research and innovation at different stages of the process and at different levels of engagement, from shaping research agendas and policies, to gathering, processing and analysing data, and assessing the outcomes of research”* (European Commission. Directorate General for Research and Innovation., 2020).
2. Open Science is an umbrella term that includes various dimensions of openness (Fecher and Friesike, 2014) and includes practices that aim to render scientific knowledge openly available, accessible, and reusable for everyone, to increase sharing of information and collaborations, and to open scientific processes to societal actors other than the scientific community. Open science builds on several key pillars, with open access, scientific publications, infrastructures, educational resources, data, resources, software, and hardware, crowdfunding and crowdsourcing, open engagement of societal actors, and open dialogue with other knowledge systems (UNESCO, 2021). Citizen Science is one of these pillars: it presents the means for open, holistic, and participatory processes of knowledge generation, enlarging the understanding of openness by including the participation of non-professional researchers (referring to individuals who may have the ability to perform research but lack formal training or professional affiliation as researchers).
3. Moreover, Citizen Science is one of the pillars also of the Responsible Research and Innovation approach (European Commission. Directorate General for Research and Innovation., 2012), which aimed to a research process designed to engage public and accountable stakeholders in science and innovation to achieve ethically acceptable, sustainable, and socially desirable research and innovation outcomes. The Responsible Research and Innovation rationale is that science and technology have the potential to change the future, but citizens, industry, and other societal stakeholders must be involved in the process. The six Responsible Research and Innovation keys are Public Engagement, Science Education, Gender Equality, Ethics, Open Science, and Governance; other common principles underlying these pillars include anticipation, inclusion, reflexivity, openness, responsiveness, and transparency.

While Open Science opens the door of academia to the world, Citizen Science invites the world into academia and science (Wehn et al., 2020). Citizen Science also includes Public Engagement aspects. In fact, Citizen Science is a research methodology that engages the public while also pursuing social and educational objectives through training and participation in science, improving scientific literacy and critical thinking, and promoting STEAM (Science, Technology, Engineering, Art, and Mathematics) careers. Moreover, Citizen Science promotes connections with decision makers for official use of citizen-generated data and to inform evidence-based policies.

Citizen Science is a term coined independently in the mid-1990s by Rick Bonney (Bonney, 1996) for public participation in research projects, and by Alan Irwin (Irwin, 1995) to refer to concepts of scientific citizenship to open up science and science policy processes to the public. Citizen Science presents the means for open, holistic, and participatory knowledge generation processes, increasing the meaning of openness by including the participation of non-professional researchers.

Citizen Science widens the scope of research and innovation and the quality and quantity of data that can be collected and analysed; it increases the robustness of the outcomes; it enables original and imaginative approaches; it leverages the so-called *wisdom-of-the-crowd*, the collective intelligence, which is often excluded from contributing to the research process; it aligns results with societal needs, values and expectations, ensuring a greater impact; it reduces time-to-market of products and services resulting from research projects; it triggers positive behavioral changes; it increases openness, and “co-ownership” of society thus encourages a bidirectional and mutual learning between science and society; it reinforces societal trust in science and increases transparency, science literacy and confidence of the public in research (European Commission. Directorate General for Research and Innovation., 2020; Farrer and Delaney, 2021). Moreover, Citizen Science should be encouraged because society is moving towards a peer-to-peer model, with citizens becoming the new decision-makers, thus, scientists should produce knowledge for citizens. Citizen Science is needed to make a sustainable transition happen (Wildschut, 2017).

Citizen Science has been developed and applied in various fields such as ecology, astronomy, medicine, genetics, engineering, and social sciences. A scientometric description of what the concept of CS Citizen Science entails indicated that there are three main dominions of Citizen Science, here ordered by their frequency: 1) one composed of biology, conservation and ecology, which utilizes Citizen Science mainly for the collection and classification of data; 2) geographic information research, in which citizens collect geographic data; 3) social sciences and epidemiology, in which the public participate in activities related to environmental issues and health (Kullenberg and Kasperowski, 2016). Citizen Science has substantial untapped potential in the field of nursing research. As a practice-embedded discipline, nursing research is uniquely positioned to benefit from the participatory and community-focused approach of Citizen Science. In particular, Citizen Science can be effectively integrated into nursing research within areas such as chronic disease management, health promotion, environmental health, and person-centered care. Nurses, as both implementers of care and researchers, are well-placed to engage patients and communities in collaborative research efforts, improving the relevance and applicability of research outcomes.

For example, in chronic disease management, nurses could partner with patients to monitor health data, track lifestyle changes, and assess treatment outcomes in real time, providing insights that would otherwise be difficult to obtain through traditional clinical research methods. Similarly, in the realm of health

promotion, Citizen Science can enable community members to take an active role in researching public health issues, thus fostering a deeper understanding of community health needs and preferences.

This paper provides a thorough examination of the methodological considerations necessary for applying Citizen Science in nursing research. We highlight essential elements for designing and implementing Citizen Science initiatives, particularly their potential to enhance community health and foster patient engagement. By reviewing previous applications and exploring future possibilities, we aim to offer a comprehensive framework for integrating citizen participation into nursing research and practice. This work serves as a methodological contribution, outlining practical strategies and considerations for effectively incorporating Citizen Science into nursing studies.

4. Citizen Science approaches

In Citizen science, engagement varies widely, from collecting data to analyzing information and even co-designing research driven by specific community needs. This approach empowers communities by enabling them to address health concerns directly, enhancing scientific literacy, and fostering civic action. Working together towards a common scientific goal can strengthen social bonds, build trust among community members, and enhance social capital (Den Broeder et al., 2016; Roche et al., 2020). Citizen science is often considered as one of the activities covered by a larger umbrella of concepts, including open science, but it is also a rapidly growing field with increasing legitimacy: it enlarges public participation in science while fostering innovative and alternative ways of knowledge production, via varied stakeholder participation and new partnerships. Many projects are now dealing with cutting-edge areas of science, such as gene editing and synthetic biology, to new audiences tackling their societal implications (Hecker et al., 2018).

Citizen Science enriches numerous scientific endeavours by connecting epistemic outcomes with societal values, including personal development, education, social innovation, and policy influence. However, certain scientific fields may offer fewer opportunities for citizen participation. It is also important to recognize that Citizen Science should not be regarded as a cost-saving strategy for scientific research: critics argue that this perspective risks framing Citizen Science as a modern neoliberal tactic that exploits citizens by leveraging unpaid labor for data, a crucial asset in our era (Vohland et al., 2021).

Citizen Science projects can be classified in different ways (Den Broeder et al., 2016). First, they can be categorized by the number of participants, e.g. mass participation projects to local monitoring projects (Roy et al., 2012). Another typology of classification is suggested by Wiggins & Crowston (2011) in which Citizen Science projects can be distinguished based on their aims: a) *action*, in which citizens and scientists jointly address local issues and concerns; b) *conservation*, in which citizen scientists focus on managing natural

resources; c) *investigation*, aimed at addressing scientific questions; d) *virtual* projects, with activities carried out remotely; e) *education*, meant to improve citizen knowledge (Wiggins and Crowston, 2011).

An alternative taxonomy proposes to classify Citizen Science projects by the type of participant engagement (that we summarized in Figure 1): a) *contributory* projects, or crowdsourcing, in which citizen scientists act as sensors, provide computing power, and/or contribute to collecting and/or analyzing data; b) *collaborative* projects, or distributed intelligence, in which citizens learn basic skills useful for the collection and the interpretation of data and have opportunities to contribute to various stages of the research process in collaboration with the researchers; c) *co-created* projects, or *bona fide* participatory science, in which citizens co-decide on research questions and types of data to be collected; d) *citizen-led* projects, or extreme Citizen Science, in which citizens are fully charge of the research design, delivery, and translation (Haklay et al., 2013; Marks et al., 2022).

FIGURE 1

Figure 1. Different Citizen Science approaches classified by volunteer engagement (Haklay et al., 2013; Marks et al., 2022).

A further classification of Citizen Science distinguishes the following different types of activities: a) *long-running Citizen Science*, in disciplines in which the collaboration with non-professional scientists is consolidated, such as ecological, biological, and weather observations, archaeology, astronomy; b) *citizen cyberscience*, that encompasses projects that leverage Internet and Web, engaging citizen scientists through both computing and communication devices; examples are volunteer computing, where participants donate unused computer resources, volunteer thinking, where participants contribute cognitive abilities, and passive sensing, which relies on sensors in mobile devices; c) *community science*, involves projects conducted within local, everyday settings to tackle local issues, participatory sensing, where researchers and citizens collaborate, Do-It-Yourself science, where participants create scientific instruments, and civic science, which fosters relationships between the public, experts, and policymakers for scientific knowledge production (Haklay et al., 2018).

In 2018, the European Citizen Science Association defined the key principles for good practice in Citizen Science (Gold, 2022; Robinson, et al., 2022), listed in table 1: serve as guiding principles to ensure the integrity, effectiveness, and ethical conduct of Citizen Science projects, and they outline the core values and standards that should be upheld in both the design and implementation of Citizen Science initiatives.

Bonney and colleagues proposed a model for developing a Citizen Science project. First, a guiding question must be defined. A team of scientists, educators, technologists, and evaluators is then created, and the team should develop, test, and refine protocols, data forms, and educational support materials.

Participants can now be recruited and trained. Data are then collected and subsequently analyzed and interpreted. Last, results are disseminated and outcomes measured (Bonney et al., 2009).

5. The reasons for scientist skepticism towards Citizen Science

The “ivory tower” paradigm that all knowledge is restricted to research institutions/universities is reductive, and exclusive and fails to recognize that much utilizable knowledge is available beyond the confines of academia. Citizen Science requires researchers to practice a certain degree of humility by stepping back and being open to learning from others (Crone, 2022).

In fact, while scientists are generally willing to participate in outreach activities like public talks or interviews, they are generally less open to engaging lay people in their own research activities. This may be because of their negative perceptions of the public’s ability to contribute to science, due to the lack of specific knowledge, skills, and training of volunteer participants (Riesch and Potter, 2014). As mentioned above, the same *deficit model* is still prevalent in science communication: scientists remain the holders of all knowledge, and as such communicate scientific information to the lay public and other stakeholders, to increase their science literacy and overcome public uncertainty and skepticism towards modern science, which is thought to be primarily caused by a lack of sufficient science knowledge (Ko, 2016).

Also, data collected by citizen scientists is sometimes considered of low accuracy or biased, limiting their usability for scientific purposes (Williams et al., 2018). Citizen Science projects are also affected by a stigma caused by the higher standards placed on them when compared to classical research methods (Collins et al., 2022). Citizens can actually gather data of quality comparable to the professional setting, i.e., with a similar error rate or degree of variation between observers (Crall et al., 2011; Lewandowski et al., 2017). Citizen Science project leaders must of course control data quality and implement quality assurance procedures (Robinson, et al., 2022; Williams et al., 2018): trust in Citizen Science projects can be enhanced when the study addresses precise research questions and the experimental design includes quality control (Collins et al., 2022).

Additionally, scientists often define Citizen Science simply as involving non-scientists in data collection. This description *de facto* limits scientists from fully appreciating how Citizen Science could benefit their research objectives. This approach, in fact, keeps the scientist wholly in charge of the scientific process and propagates the narrative of Citizen Science being only a tool to educate and increase public understanding of science. Scientists do perceive the societal benefits of Citizen Science (it fosters ownership, engagement, and strengthens researcher-community relationships; it enhances the trust of science, and promotes science careers), but they do not fully appreciate the advantages that Citizen Science can offer them as well (Collins et al., 2022). However, Citizen Science can become a truly participatory enterprise only if the citizen

scientists are actively involved in decision-making at some level in the scientific process (van Tuyl and Scholte-Voshaar, 2011). Mere data collection fails to democratise the process, does not accomplish the multifaceted engagement with science offered by Citizen Science (Martin, 2017), and can be a disappointing experience for the citizen scientists (Roche et al., 2022).

Another holdback often imagined by scientists is the effort in terms of time and resource management, because volunteers cannot be expected to be involved regularly in shifts or participate in the project for long periods (Riesch and Potter, 2014).

Characteristics of a research project that can exploit Citizen Science

Citizen Science, similarly to any other scientific approach, thrives when tackling well-defined and specific questions. Therefore, to ensure that data collected through Citizen Science is suitable for its intended use, the objectives must be clearly articulated and delineated. The suitability for a Citizen Science approach increases when the project has a clear aim, public engagement is important for its realization, resources are available, a large-scale sampling is required, the proposed protocol is simple, and participants are given a good reason to join the project (Pocock et al., 2014).

The types of data that can be collected in Citizen Science project are various: records or observations detailing location and time; multimedia inputs such as images, video or audio; quantitative measurements; physical samples; sensor-based measurements detecting phenomena beyond human observation like radiation, temperature, or noise; data sourced from social media; tasks involving the classification of pre-existing data, which are often intricate for automation but straightforward for human interpretation, such as pattern recognition (Pocock et al., 2014), at least prior to the development of devoted artificial intelligence approach.

Researchers should be made aware that Citizen Science is a research approach like any other, with limitations and biases that should be considered and controlled (Gold, 2022). Citizen Science is an underexploited but valid research method that involves lay people as an integral part of the scientific process, not just in outreach activities or other initiatives connecting science to society (Crone, 2022). Every research method has its advantages and disadvantages: in a research lab, all the conditions are controlled allowing causal conclusions; in the real world, we can reach out to communities that possibly would not come to the lab. The strength lies in the combination of methods, where the disadvantages of one method can be compensated by the advantages of another one (Crone, 2022).

Citizen science online platforms are transforming how individuals contribute to scientific research and may serve as a source of examples for researchers interested in collaborating and/or creating Citizen Science projects. *Zooniverse* empowers volunteers to analyze astronomical images, classify wildlife, and even transcribe historical documents, making research accessible to the masses. *CitizenScience.gov* connects

citizens from the United States of America with government-led projects, such as tracking invasive species or monitoring air quality. Meanwhile, SciStarter serves as a hub for discovering diverse Citizen Science projects across disciplines, enabling collaboration between enthusiasts and researchers. In Europe, *eu.citizen-science* fosters collaboration between researchers and the public by providing access to tools, resources, and projects aimed at tackling societal challenges. These platforms exemplify how technology can bridge the gap between professional science and public participation, democratizing discovery and innovation.

6. A change in the researcher perspective is needed to implement Citizen Science

Narrowly defining Citizen Science as citizen participation in data collection counters efforts to involve the public at stages of research where citizens have more power, such as in the development of research questions. The social aspect of Citizen Science has proven to be beneficial for all the subjects involved, as it is rewarding for scientists, has an important positive outcome for volunteers, and helps open up the scientific community to the general public.

While some researchers recognize the other publics as stakeholders in scientific research, others do not find public support to be a strong motivator for engagement; their primary motivation for using Citizen Science is the opportunity to collect data that otherwise would be out of reach (Collins et al., 2022). Ongoing evaluation against the objectives of the engagement, e.g. through a survey of participants or informal collection of feedback, should also be standard practice alongside the monitoring of scientific aspects of Citizen Science projects. For projects funded on the premise of public participation in science, the engagement process should be considered as important as the scientific aspects of the Citizen Science projects and managed accordingly.

The broader community of scientists is yet to be convinced that Citizen Science can produce worthwhile results and, therefore, is worth pursuing (Riesch and Potter, 2014). The main limitations perceived by scientists are that Citizen Science does not fit with their research objectives (Collins et al., 2022), a lack of value (Golumbic et al., 2017) or a mistrust in the data collected (Riesch and Potter, 2014).

On the other hand, researchers with experience in Citizen Science manifested the need for support to run Citizen Science projects, namely in terms of experienced personnel who can help in engagement and communication, in programming apps and websites, or in writing projects likely to get funded (Collins et al., 2022).

In addition to a change in researcher mindset, other institutional changes are required to allow researchers to fully embrace Citizen Science: recognition of Citizen Science in academic curricula; training, learning, mutual events to share best practices and failures to enable reuse of existing technologies; support for national observatories Citizen Science and the creation of specific thematic networks; shared repositories and infrastructures; tools to facilitate sustainability, scalability, and replicability of existing Citizen Science

projects that have demonstrated impact; introduction of innovations to the market, new business models that make this possible; appropriate channels to facilitate stronger science-policy linkages for the benefit of society.

7. Citizen Science in nursing

Nursing research, as a practice-based discipline, involves systematic investigations aimed at advancing knowledge in the nursing profession and improving patient care. It is grounded in empirical studies that aim to enhance clinical practices, inform policy, and address pressing health concerns. Nursing research typically includes studies on patient outcomes, interventions, chronic disease management, health promotion, and the social determinants of health. It is inherently interdisciplinary, drawing from fields such as medicine, psychology, sociology, and public health.

The systematic reviews carried out by Torr -Pons et al. and by Todowede et al. (Todowede et al., 2023; Torr -Pons et al., 2024) found that previous Citizen Science studies in nursing covered several key areas, including environmental health, food safety, environmental improvements, chronic diseases, COVID-19, and mental health. In the realm of environmental health, Citizen Science has been employed to tackle issues such as radon exposure and wood smoke pollution (Cardarelli et al., 2021; Evans-Agnew et al., 2022; Hahn et al., 2020). In the area of food safety, the focus has been on concerns like food insecurity and obesity (Tuckett et al., 2022). Additionally, citizen engagement has explored environmental improvements related to physical activity (Tuckett et al., 2022) and support for breastfeeding (Rowbotham et al., 2022). Research on chronic diseases emphasizes the importance of integrating patient perspectives to enhance healthcare. Furthermore, studies on COVID-19 have mainly concentrated on tracking symptoms across different demographic groups (Valdez et al., 2021). In addition, Citizen Science seems to be a feasible approach in the field of mental health and can complement other participatory methods. In fact, it offers the potential to foster active involvement, engagement, and knowledge creation with the public. Data collection in these studies often combines elements of both the "Quantified Self" approach and the "Lived-Experiences" approach (Torr -Pons et al., 2024). Through the "Quantified Self approach", individuals use devices like wearables or health apps to track their own health data, such as sleep patterns, physical activity, and diet. The Lived-Experiences approach focuses on capturing the personal stories and subjective experiences of patients and caregivers through face-to-face surveys and group discussions (Torr -Pons et al., 2024). The levels of participation of patients in Citizen Science nursing studies varied; in some studies, citizens were only involved in data collection (Cardarelli et al., 2021; Hobensack et al., 2023; Rowbotham et al., 2022; South et al., 2022). A few studies even invited participants to co-author papers or take part in the review process (Tran et al., 2019). This reflects a shift toward more collaborative and participatory research models in nursing.

Healthcare professionals have a role in preventing and treating illness and supporting patients through the care journey. Nurses, in particular, are the professionals closest to patients because of the functions they perform. Nursing care is a *“skilled, safe, high-quality, holistic, ethical, collaborative, individualized, interpersonal caring process that is planned and designed based on the best evidence available, and results in positive patient outcomes, optimization of health, palliation of symptoms, or a peaceful death”* (DalPezzo, 2009). Nursing is a distinct science and practice that is not limited to direct care roles. Nurses are employed in a variety of clinical and non-clinical roles and settings (ICN, 2021). Because of the nature of the profession, a relationship of trust is often established between the patient and the nurse, which makes it possible to get to the core of the patient's experiences and needs. To study these phenomena based on patient needs, the Citizen Science approach can make nursing research more effective for at least three reasons.

First, Citizen Science allows for the inclusion of participant perspectives starting from the research problem formulation and subsequent study design. According to the International Council of Nursing *“Nursing encompasses autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well and in all settings. Nursing includes the promotion of health, prevention of illness, and the care of ill, disabled and dying people. Advocacy, promotion of a safe environment, research, participation in shaping health policy and in patient and health systems management, and education are also key nursing roles”* (ICN, 2021). Nursing touches people's daily lives, in both healthy and unhealthy conditions, and is therefore closely connected to citizens' interests. Indeed, as reported by the National Institute of Health (NIH) Citizen Science Working Group in Biomedicine (National Institute of Health, 2021):

- People are creative and can provide not only data, but also critical context and unique insights not available through traditional approaches.
- People are eager and able to solve problems when given the right tools and opportunities - not just technical tools and interfaces but approaches that enable creativity and insight.
- Patients, caregivers, those affected by health challenges, and healthy individuals may be highly motivated to collect and share personal health data to aid in research that helps others in similar circumstances.

Secondly, nursing as an art and science recognizes patient participation in care as one of the key scientific criteria of its discipline (Benner and Wrubel, 1989; Dutt, 1995; Gadamer, 2004; McCaffrey, G., 2023).

As reported by Harmer & Henderson in 1955 (Harmer and Henderson, 1955) in their well-known definition of nursing, the specific function of a nurse is to take care of individuals, in a healthy or unhealthy condition, to help them to perform some acts to maintain a healthy status or to heal (or to prepare them for a peaceful death); acts that they would perform alone if they had the strength, the will or knowledge and to improve their active participation to help them regain their independence as soon as possible.

Involving patients and caregivers not only in the actions of care, but also in the construction phases of knowledge, could help to consolidate the professional basis of care.

Finally, the discipline of nursing is one of the early medical humanities to use and refine qualitative research methods to learn more about the inner world and experiences of patients (Morse, 2012).

The involvement of patients and caregivers in quali-quantitative research could significantly and genuinely improve outcomes such as treatment adherence, self-care skills, adaptation to new living conditions, fewer complications, conscious use of health systems, and citizens' greater trust in science.

Key considerations and domains of Citizen Science in nursing research

In developing the 'key considerations' for integrating Citizen Science into nursing research, we undertook a narrative synthesis of themes and insights identified across a range of relevant studies in the existing literature. The synthesis process was iterative, involving a continuous review and critical analysis of studies that discussed both the opportunities and challenges of applying Citizen Science in the context of nursing. By identifying recurring insights and common themes, we were able to derive these considerations, which reflect the multifaceted nature of Citizen Science and its potential to enhance nursing research. This approach ensures that the key considerations are evidence-based and grounded in the lived experiences and insights of both healthcare professionals and the public.

Citizen Science encompasses a range of notions and approaches, often overlapping with related concepts like Patient and Public Involvement and Engagement in health and care research. Citizen Science primarily focuses on involving members of the public or different communities in the research process, with the principal aim of generating scientific knowledge or collecting data at scale. Participants contribute to various stages of research, such as data collection, analysis, and sometimes even study design. While the primary aim is scientific advancement, democratization and enhanced collaboration and trust building between professional researchers and the public are important aspects and/or potential benefits. On the other hand, Patient and Public Involvement and Engagement centres on involving patients and the public in shaping health and care research to ensure it aligns with their needs and priorities. The primary focus is often on influencing research decisions by providing lived experiences, insights, and feedback to shape the research agenda, which distinguishes it from Citizen Science models primarily focused on generating data or performing scientific tasks (Vaughn and Jacquez, 2020).

When applied to health issues, Citizen Science, like Patient and Public Involvement and Engagement, emphasizes co-creation and collaboration between scientists and citizens, but often retains the primary ownership of the research and findings with professional researchers. Learning from Patient and Public Involvement and Engagement, Citizen Science should prioritize shared decision-making and give significant

weight to the voices of patients and the public, emphasizing their role as equal partners in the research process (Burduladze et al., 2024; Kaisler and Missbach, 2019).

In health research, there exists a longstanding tradition of layperson participation, exemplified by Patient and Public Involvement and Engagement approaches such as "Community-Based Participatory Research" (Collins et al., 2018) or "Participatory Health Research" (Duea et al., 2022). While these approaches share some similarities with Citizen Science, they differ in significant ways. A notable characteristic of Citizen Science is the broad and often undifferentiated use of the term "citizen". While the ideal is often presented as "anyone can participate", empirical evidence suggests that participation is not always universally representative, sometimes skewing towards individuals with higher education levels or belonging to specific demographic groups (Allf et al., 2022). This contrasts sharply with the terminology used in Patient and Public Involvement and Engagement, Community-Based Participatory Research, or Participatory Health Research, which employ more specific identifiers like "patient," "service user," "carer," "public member," or "community member," often defined by a shared health condition, lived experience, geographic location, or cultural identity.

Rooted in the tradition of action research, they primarily aim at the ongoing transformation of specific life conditions or practices and are heavily focused on the public health sector, often addressing the needs of socially disadvantaged populations. Citizen Science often involves broadly defined "citizens" and historically has not typically prioritized specific lived experiences or disadvantages in the way Patient and Public Involvement and Engagement, Community-Based Participatory Research, or Participatory Health Research do (Heyen et al., 2022). However, as Citizen Science is more and more applied to medicine and health-related projects, it is increasingly turning its attention to underserved communities and local contexts with dedicated projects (Barrie et al., 2019; Chrisinger and King, 2018; Grootjans et al., 2022).

Furthermore, these methodologies actively build equitable partnerships that include community members/laypersons alongside relevant stakeholders and professionals, whereas Citizen Science mainly seeks the participation of laypersons (Heyen et al., 2022).

A how-to guide for reliable Citizen Science in nursing

Based on the existing literature (Haklay et al., 2021; Marks et al., 2023, 2022; Rowbotham et al., 2023; Smith et al., 2019) and drawing on the synergy between community engagement and nursing expertise, we present key considerations to ensure the effectiveness, reliability, and inclusivity of Citizen Science initiatives in nursing (Figure 2).

FIGURE 2

Figure 2. Critical factors to ensure the effectiveness, reliability, and inclusivity of Citizen Science initiatives in nursing. This figure is based on existing literature written by Haklay et al., 2021; Marks et al., 2023, 2022; Rowbotham et al., 2023; Smith et al., 2019.

1. **DEFINING RESEARCH QUESTIONS IN COLLABORATION WITH COMMUNITIES:** Begin by collaboratively defining health objectives and research questions with the communities involved. Engage citizens in the identification of prevalent health issues, ensuring that the research aligns with their needs and priorities. This step sets the foundation for a relevant and impactful Citizen Science project within the healthcare context. Adopting a participatory model could emphasize collaborative decision-making and shared responsibilities. A participatory model aligns with nursing principles of patient-centered care and community engagement, providing a methodological framework that fosters mutual trust and respect between researchers and participants.
2. **NURSING LEADERSHIP AND COMMUNITY PARTNERSHIPS:** Leverage nursing leadership to establish strong partnerships with communities. Nurses, as trusted healthcare professionals, can play a central role in bridging the gap between the scientific community and citizens. Involve community members in project planning, design, and decision-making processes. Tailor the project to address community needs and concerns, ensuring the active participation of citizens throughout the research journey.
3. **PATIENT-CENTERED RESEARCH PROTOCOLS:** Develop robust protocols for data collection, ensuring they are standardized and easy for citizen participants to adhere to. Consider the expertise of nurses in clinical assessments and patient interactions when designing protocols. Clearly communicate methodologies, data formats, and any necessary training materials to clarify any doubts or unclear aspects. Emphasize the importance of consistency in enhancing the reliability and validity of collected data. Develop transparent and inclusive processes for data analysis, e.g. through involvement of participants in all stages of the process, operational phases and potential discussions. Ensure that data collection methods are feasible, inclusive, and respect the privacy and dignity of participants. Consider involving participants in interpreting findings, fostering a collaborative approach to knowledge generation. Collaborate for the interpretations of findings with the participants, reinforcing a sense of shared ownership in the research outcomes. Clearly communicate results to both the scientific community and participants.
4. **TECHNOLOGY INTEGRATION:** Leverage technology to facilitate data collection, analysis, and communication. Explore user-friendly platforms, mobile applications, and online tools, preferably open source, that enhance participant engagement and streamline data management. Provide necessary training and support to ensure participants can effectively use technology.
5. **INTEGRATION IN HEALTH EDUCATION:** The nurse has a fundamental role in educating people and these skills can also be used and applied in Citizen Science projects. Nurses can develop an educational project in detail, identifying materials, ways and strategies to engage and raise awareness inside hospitals and in

different contexts like outpatient clinics, schools, communities, and reception centers. Educational skills can effectively contribute to the dissemination of Citizen Science projects.

6. QUALITY MONITORING: Define quality monitoring measures and strategies to validate data collected by citizen scientists. Identify monitoring tools and apply them consistently. Ensure feedback methods for participants to promote a sense of ownership and involvement in the project.

7. ETHICAL CONSIDERATIONS: Ensure that ethical issues are given priority by obtaining informed consent from participants. Explain clearly and accurately the purpose, risks and benefits of the research project. Ensure and monitor the adoption of privacy and data protection measures in accordance with ethical standards and regulations governing Citizen Science research.

8. DIVERSITY, EQUITY, AND INCLUSION: Ensure respect for diversity and inclusion in the recruitment of participants. Identify and manage potential barriers to participation, such as language, accessibility and cultural considerations. Implement strategies to involve everyone, especially underrepresented groups. Ensure equitable returns for participants' contributions. Involving citizens requires meaningful engagement, mechanisms for feedback and accountability, and transparent communication.

9. SUSTAINABILITY AND IMPACT ASSESSMENT: Plan for the long-term sustainability of the project, considering funding, resources, and ongoing community engagement. Assess the impact of the Citizen Science initiative on both the scientific field and the participating communities, adapting and refining methodologies for future projects.

Table 1 summarizes the ten principles of Citizen Science, the nine nursing domains of research, and the International Council of Nurses' definition of nursing.

Table 1. Synthesis of the integration of Citizen Science in Nursing research. The table is based on the synthesis of the evidence about the use of Citizen Science in the nursing field.

TABLE 1

LIMITATION AND RISK OF CITIZEN SCIENCE APPROACH IN NURSING RESEARCH

While Citizen Science holds great promise for advancing nursing research, it is essential to acknowledge the limitations and risks associated with its implementation. Addressing these concerns during the design and execution of Citizen Science studies is vital for ensuring their validity, ethical integrity, and long-term sustainability.

DATA QUALITY AND RELIABILITY

One of the main concerns about incorporating Citizen Science into nursing research is the variability in data quality. Unlike professional researchers, citizen participants may lack the expertise and training required for

the accurate and reliable collection of data. This variation can lead to inconsistencies, errors, or biases that compromise the integrity of research findings (Baard and Sandin, 2022). To mitigate these risks, it is crucial to provide comprehensive training and support to participants. Ensuring they understand the data collection tools and methodologies, and adhere to standardized protocols, is essential.

ETHICAL CONSIDERATION

The involvement of non-expert participants in nursing research raises several ethical issues, particularly concerning informed consent, privacy, and confidentiality. Citizen Science studies often collect sensitive health data, making careful consideration of ethical principles paramount (Christine and Thinyane, 2021). It is vital to ensure that participants fully understand the risks associated with sharing personal health information to maintain ethical standards. Vulnerable populations may struggle to comprehend the implications of their participation, leading to potential unintentional harm or exploitation. Hence, researchers must prioritize clear and transparent informed consent processes, along with robust safeguards to protect participant privacy and confidentiality.

BIAS OF REPRESENTATIVENESS

Citizen Science initiatives typically rely on volunteer participation, which can introduce selection bias. Participants may self-select based on personal interests or experiences, resulting in an overrepresentation of certain demographic groups or health conditions. In nursing research, this bias can limit the generalizability of findings, particularly when the target population is diverse and encompasses individuals with varied healthcare needs (Backstrom et al., 2025). Researchers should implement strategies to recruit a diverse participant pool and ensure that findings reflect a wide range of experiences and needs within the community. This may involve outreach to underrepresented groups and promoting inclusive participation across different socioeconomic, cultural, and health backgrounds.

COLLABORATION CHALLENGES

Effective collaboration between researchers and citizen participants is crucial for the success of Citizen Science in nursing research. However, challenges may arise regarding expectations and the division of roles. Citizen participants might have limited experience with research processes, leading to misunderstandings or discrepancies in expectations. Such challenges can hinder the smooth progression of research activities and affect the quality of outcomes (Roche et al., 2020). To address this, clear communication, well-defined roles, and ongoing support throughout the research process are essential. Researchers should engage citizen participants as active collaborators rather than passive subjects, ensuring their contributions are acknowledged and valued.

SUSTAINABILITY AND LONG-TERM ENGAGEMENT

Maintaining long-term participation in Citizen Science initiatives can be challenging. Many Citizen Science projects rely on the initial enthusiasm and motivation of participants, which may decline over time, resulting in participant attrition and incomplete datasets. This is particularly relevant in nursing research, where longitudinal data collection may be necessary (Torró-Pons et al., 2024). To enhance retention, it is important to provide ongoing support, feedback, and recognition of participant contributions. Researchers can explore methods to incentivize continued engagement, such as offering educational opportunities, hosting community-building activities, or acknowledging citizen contributions in research publications.

CONCLUSIONS

Through Citizen Science, the practice of scientific research is no longer restricted to experts but becomes an inclusive process. Citizens become able to directly participate in a scientific study and to make a real contribution to the progress of science, sometimes by simply using an app on their mobile phone, just like when they daily interact with the trackers that count how many steps they take, what they eat, and the sports they practice. With Citizen Science, citizens become actors in a scientific project by collecting and perhaps analysing valuable information, for example, on their state of health. Both professional and citizen scientists benefit from these projects and take part in multiple stages of the scientific process, such as the development of research questions, the setup of a method, the collection and analysis of data, and the communication of results. These benefits can ultimately translate into the opportunity for citizens to influence sector policies and receive feedback, for instance, on how their data ~~are~~ is being used and what the results of the study are. The results are then published in an open-access format, adding value for the community, and promoting the goal of universal access to scientific data and information.

Nonetheless, while Citizen Science aims to transform research by giving the public a more active role, in many projects the critical power relationships including selection of the research area, construction of the study, or decision on the appropriate methods may rest on the professional members of the team. In this manner, the typical hierarchies along with unequal power relations continue to exist, and hence the change that can be brought about by Citizen Science is undermined. Furthermore, the ability to participate in Citizen Science is not always equitably shared among various groups and communities, which brings up issues of equity and how representative the research results are. Without deliberate efforts to challenge these dynamics, Citizen Science may, arguably, continue to reinforce, rather than dismantle, the biases built into the commissioning and designing of research.

Integrating Citizen Science in nursing represents a dynamic approach to advancing healthcare research. By embracing the methodological perspectives outlined in this article, nursing professionals can lead and contribute to projects that not only generate valuable insights but also foster a collaborative and patient-

centered approach to healthcare inquiry. This intersection holds the potential to transform the landscape of healthcare research, emphasizing inclusivity, community empowerment, and the holistic well-being of individuals and populations.

Implementing successful Citizen Science projects requires a thoughtful and systematic approach. By incorporating these methodological considerations, researchers can design projects that not only generate valuable scientific knowledge but also foster meaningful collaboration between scientists and citizens. This comprehensive guide aims to provide a foundation for researchers, practitioners, and community leaders embarking on the journey of Citizen Science, promoting a collective and inclusive approach to scientific inquiry.

Conflict of interest: none

Funding: no external funding

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Table 1. Synthesis of the integration of Citizen Science in Nursing research. The table is based on the synthesis of the evidence about the use of Citizen Science in the Nursing field.

Citizen Science key principles (European Citizen Science Association – ECSA 2018) :	Citizen Science & Nursing domains of research	Nursing (International Council of Nurses’ definition (ICN, 2021))
1. Citizen Science projects actively involve citizens in scientific endeavours that generates new knowledge or understanding; 2. Citizen Science projects have a genuine science outcome; 3. Both professional scientists and citizen scientists benefit from taking part in citizen science projects; 4. Citizen scientists may, if they wish, participate in multiple stages of the scientific process; 5. Citizen scientists receive feedback from the project; 6. Citizen Science is considered a research approach like any other, with limitations and biases that should be considered and controlled for; 7. Citizen Science project data and meta-data are made publicly available and, where possible, results are published in an open access format; 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	1. Defining research questions in collaboration with communities 2. Nursing leadership and community partnership 3. Patient-centered research protocol 4. Technology integration 5. Integration in health education 6. Quality monitoring 7. Ethical considerations 8. Diversity, equity and inclusion 9. Sustainability and impact assessment	Nursing encompasses autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well and in all settings. Nursing includes the promotion of health, prevention of illness, and the care of ill, disabled and dying people. Advocacy, promotion of a safe environment, research, participation in shaping health policy and in patient and health systems management, and education are also key nursing roles.

ethical issues surrounding copyright, intellectual property, data sharing agreements, confidentiality, attribution, and the environmental impact of any activities.		
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