

## EDITORIAL

## CITIZEN SCIENCE

### HIGHLIGHTS

1. Research focused on the real needs of the citizen is necessary
2. The citizen needs to be involved in the research cycle
3. Citizen Science advocates the value of the citizen as a co-researcher
4. Nursing needs to prepare for this mode of co-creation of knowledge

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The participative encouragement of the citizen in relation to the various dimensions of life in society has been happening more and more. Several initiatives are stimulated in view of the active involvement of the citizen, as for example: in political management, health, and science.

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In political management, the participatory budget, which aims to promote active citizenship and participatory democracy based on direct consultation with citizens, giving them the opportunity to propose and elect what they consider to be of interest to society. In health, the stimulus of the person-centered care model, which seeks to respond to the real needs and preferences of the citizen, healthy or ill. In science, the paradigm of Citizen and Open Science, which is "doing research with the citizen", instead of research "for the citizen", and the logic that "knowledge belongs to all and for all".

Citizen-centered care is a good practice, which nursing should build on. But if we want citizen-centered care, we need to empower researchers to develop research that focuses on the real needs of the citizen - Patient and Public Involvement in Research. That is, citizen involvement in the different stages of the research cycle not as a participant, but as a co-researcher.

Citizen Science is characterized by the ability to involve citizens (patient, caregiver, ordinary citizen) in scientific processes, reflected in the strong cooperation between these citizens and the scientific community. In this view, it brings the democratization of science, by the inclusion of citizens, regardless of their education, health status or experience in the processes of codesign, co-creation and co-validation of knowledge. Therefore, it also integrates the ability to communicate science, in a simple and accessible format, with the goal of enhancing citizen literacy.

With the ballast of Citizen Science comes new challenges for all researchers, based on the conception of a more open science, which aims to open the entire scientific process, enhancing transparency and social and scientific responsibility, including, for example, making (meta)data available in open access. Thus, this approach to doing science reflects a flexible umbrella of strategies, which can be adapted and applied to various disciplines, in other words, in health and beyond, and which in essence aim at involving the citizen in scientific activities to build new knowledge or products.

These strategies favor science through innovation, understanding and co-creation of truly genuine results. In addition to providing benefits to citizens by fostering their learning, personal pleasure/satisfaction in collaborating/co-creating in finding solutions to issues of local, national, or international relevance, and thereby bringing new knowledge, innovation, and influencing policies.

Citizen Science projects involve the citizen in the different stages of the life cycle of the projects, which can range from their collaboration: i) in the delineation of the scientific question; ii) in the definition of the methods to be used; iii) in the collection and analysis of data; iv) and, in the communication of the research results. Therefore, in the European agenda for competitive funding, there is a growing interest in patient involvement and in particular an interest focused on the involvement of the patient and the general public<sup>1</sup>.

This dynamic is currently reflected in the sections of the calls to these competitive funds, where there is, in the application forms, a space dedicated to the operationalization of this issue. As an example, the calls of the Cost Actions - European Cooperation in Science & Technology initiatives (<https://www.cost.eu/>), have a specific section for the researchers of the consortium to expose how they will operationalize the involvement of stakeholders, as does the EU Joint Programme - Neurodegenerative Disease Research (<https://www.neurodegenerationresearch.eu/>), which has also given emphasis to this dimension in the projects it funds, and has even defined strategies for the implementation of citizen involvement in research projects<sup>2</sup>.

Expressions such as "public and patient involvement", "social responsibility", "responsible research", "public engagement", "collaborative research", "co-creation", "involvement of stakeholders", "citizen scientist" reflect the evolution in the methods of building science and the break with the traditional paradigms of doing science, occurring a clear tendency of reorganization of these methods, in favor of citizenship by the co-editing of science in co-production (society and researchers). Citizen Science is thus a method

how science is being thought, created, communicated, and extended to society, aligning the processes and products of science with the expectations, needs and challenges of contemporary society.

With this paradigm rupture, great challenges arise, and new reflections are urgently needed, such as the issues surrounding the legal and ethical dimensions resulting from this involvement (given that this citizen is not a participant, but a citizen scientist), as well as issues regarding copyright, intellectual property, agreements on data sharing and confidentiality, as well as the very limitations and biases of this paradigm of doing science. Therefore, the discipline of nursing, too, needs to prepare for this disruptive way of building and disseminating its knowledge, and profound reflections and metamorphoses within the ecosystems where research takes place are already taking place, this editorial being (yet) another contribution to the path ahead!

## REFERENCES

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