

# Diàleg sobre ciència ciutadana i el seu impacte

IV Jornada UPC de Ciència Oberta  
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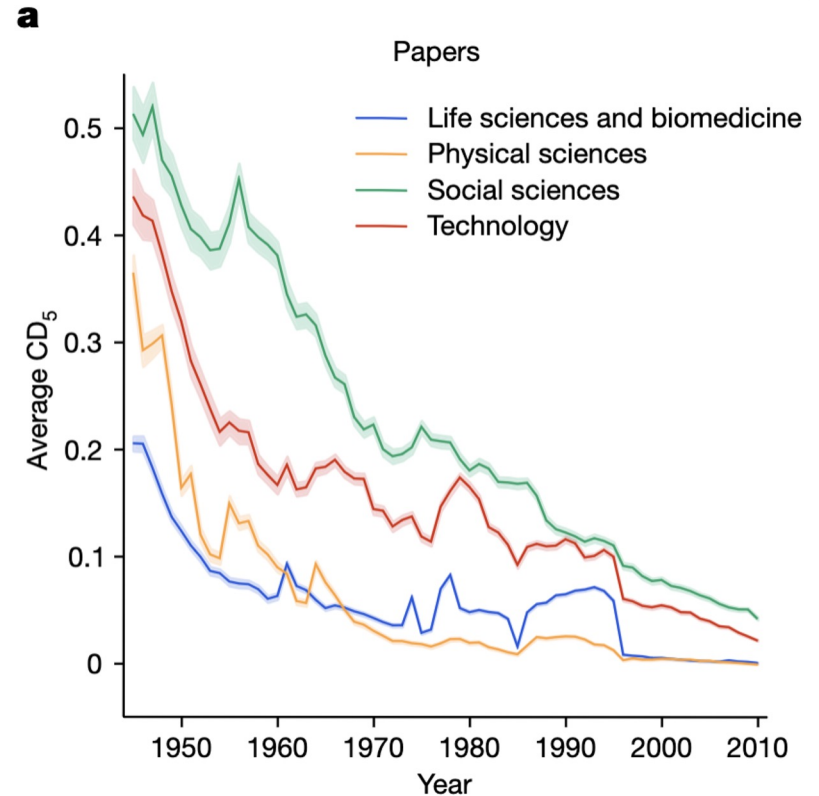
Roberto Bolaño, 2666

La libertad es un número  
primo.



# La recerca científica

“... a marked decline in disruptive science and technology over time. [...] We attribute this trend in part to scientists' and inventors' **reliance on a narrower set of existing knowledge.**”



# It is time [...] to address the ethics of inclusion

Strauss, D. H., White, S. A., & Bierer, B. E. (2021). Justice, diversity, and research ethics review. *Science*, 371(6535), 1209-1211. <https://doi.org/doi/10.1126/science.abf2170>



## POLICY FORUM

### ETHICS AND DIVERSITY

# Justice, diversity, and research ethics review

It is time for institutional review boards and research ethics committees to address the ethics of inclusion

By David H. Strauss<sup>1,2</sup>, Sarah A. White<sup>1,3</sup>, Barbara E. Bierer<sup>1,4</sup>

The disproportionate impact of COVID-19 on certain populations, such as Black, Latinx, and Indigenous populations in the United States, has focused attention on inequalities in health and on the need to increase enrollment of racial and ethnic minorities and other underrepresented groups in biomedical research (1). Yet too often, in the United States and globally, participant enrollment in research has not reflected the demographic composition of the general population, those affected by the health conditions being studied, or those for whom the investigational product is intended (2), with racial and ethnic minorities and the young and the elderly, among others, being consistently underrepresented (3). Underlying causes for this underrepresentation have been described (4, 5), but change has been slow. Notwithstanding the roles of other stakeholders in addressing this issue, we maintain that the specific value of institutional review boards (IRBs) and research ethics committees (RECs) in promoting diversity has been underrecognized and their authority underutilized. Here, we substantiate the role of and outline practical steps for the IRB and REC (hereafter “IRB”) to help achieve greater diversity in clinical research.

The appropriate inclusion of diverse populations in clinical research is necessary if we are to understand how biological variability and social determinants of health contribute to disease prevalence, transmission, course, experience of illness, and treatment outcome. The inclusion of understudied and underserved groups informs clinical decision-making and health policy and can

serve efforts to address mistrust of research and health care (6, 7). Responsibility to the goals of diversity lies with all stakeholders in the clinical research enterprise (8), and a commitment to diversity, individually and collaboratively, by research sponsors, funders, academic institutions, contract research organizations, study sites, investigators, and IRBs is necessary.

#### RESPECT, BENEFICENCE, JUSTICE

Most regulated clinical research undergoes obligate review and approval by an IRB. IRBs are charged with safeguarding the rights and well-being of human participants in accordance with the foundational tenets of respect for persons, beneficence, and justice, as described in the Belmont Report (8). An IRB’s ethical responsibilities with regard to diversity derive from these and other principles, guidelines, and standards (9, 10).

The discussion of justice in Belmont cites “moral requirements that there be fair procedures and outcomes in the selection of research subjects.” As Belmont and other codes of ethics emerged from a historical backdrop of abuse and injustice in research, “fair procedures” have been applied by IRBs largely (and, we believe, too narrowly) to ensure that subjects are not exploited and enrolled as a matter of convenience. The idea of justice within the Belmont Report also includes the notion of access to the benefits of research (i.e., knowledge gained); this has direct implications for populations that have been understudied, whether incidentally or systematically. Subject selection cannot be equitable, and the requirements of justice cannot be met, when there is de facto exclusion of understudied populations.

This notion of justice is supported by the World Health Organization’s International Ethical Guidelines for Health-related Research Involving Humans, Guideline 3, which states, “In cases where the underrepresentation of particular groups results in or perpetuates health disparities, equity may

require special efforts to include members of those populations in research” (9), and by the World Medical Association Declaration of Helsinki, which states, “Groups that are underrepresented in medical research should be provided appropriate access to participation in research” (10). Therefore, consideration of diversity is essential to the question of fairness in subject selection and to IRB review.

Diversity in clinical research is responsive to the principle of beneficence, which places priority on the welfare of research participants and creates the obligation that research presents a favorable balance of benefit to risk, after risks and burdens have been minimized. In calling for “maximization of benefits” in the research, Belmont directs attention to both individual benefit and to the broader value of research to society. A clinical research enterprise that is not inclusive does not adequately address the health needs of a diverse society. Group differences in susceptibility to disease and in treatment outcome can only be identified when those groups are studied. It is the obligation of an IRB to maximize benefits through the inclusion of understudied groups in a manner that is consistent with the study aims and does not introduce unacceptable harm or burden.

Belmont describes two ethical convictions in relation to respect for persons, self-determination, and decision-making: the obligations to treat individuals as autonomous agents and to protect those with diminished autonomy. IRBs provide additional safeguards for research involving participants with compromised voluntariness (e.g., prisoners) or impaired comprehension. With regard to the inclusion of diverse populations, respect for persons demands efforts to foster informed and autonomous decision-making and, therefore, to address common barriers posed by age, language, culture, and educational disadvantage. Respect for persons requires the identification of opportunities and resources to engage understudied populations and to enhance awareness, access, and inclusion in research (4, 6). It also demands modification of those aspects of research and of consent that inadvertently limit the participation of understudied populations. For example, although inclusion of non-English speakers in a study may involve additional expenses of translation and/or interpreters, it strengthens the commitment to autonomy and justice.

The ethical positions presented above compel attention to inclusion of diverse populations in clinical research and define a specific duty for the IRB. In a 2019 survey (11), a majority of IRB chairs, IRB ad-

# PARTNERS IN SCIENCE

The people who should benefit from research are increasingly shaping how it is done.

BY CASSANDRA WILLYARD, MEGAN SCUDELLARI AND LINDA NORDLING

Valerie Blue Bird Jernigan knew she had to break some standard scientific practices when she started her latest research project. One of the first things to go was the usual concept of a control group — people who would not receive interventions to encourage healthy eating. That wouldn't be fair to the people of the Osage Nation, a Native American people in northeastern Oklahoma.

Another concept to ditch was the idea that she was studying a group at all. Jernigan, a public-health researcher, who is Native American herself, has treated the Osage people as equal partners from the first day of the project. It took two years and seemingly endless rounds of community discussions to get the study off the ground, but Jernigan wouldn't have had it any other way. This kind of research "isn't just about proving your hypothesis," she says. It's more about improving people's lives and, at the same time, helping them gain the skills to do science.

Jernigan's approach, often referred to as community-based participatory research, has been gaining traction for the past two decades. It has become particularly important for research that involves indigenous and other populations who have been mistreated by scientists in the past. The Havasupai tribe in Arizona, for example, waged a lengthy legal battle with Arizona State University in Phoenix over researchers' misuse of blood samples that the tribe had provided for a diabetes study in the 1990s. The samples were eventually returned as part of a settlement two decades later. The lessons learnt from the event have set the tone for how best to do research involving Native Americans.

Community participation has become the norm. "In minority communities, it's probably the primary research methodology," says public-health researcher Alexandra Adams, director of the Center for American Indian and Rural Health Equity at Montana State University in Bozeman. "It reduces mistrust, it improves dissemination and it improves cooperation." The goal of such efforts is the co-production of research, in which the stakeholders who are supposed to benefit from a strand of research become active partners in conducting it. Scientists from disciplines as varied as archaeology, public health and climate change have embraced the approach, working with community members on many different aspects, from formulating study questions and design, to doing experiments and analysing and reporting results.

Nations talked to three groups that have built successful co-production projects: their experiences reveal the challenges and rewards that come with the open and collaborative exchange of ideas. The work veers away from the standard outputs of sciences, such as talks and papers, and expands the idea of what it means to be a scientist and a collaborator.



A PLACE AT THE TABLE

Jernigan's latest project with the Osage people wasn't wholly her idea. It started with Raymond Red Corn. As a child growing up in the Osage Nation, Red Corn helped his parents to harvest the dusky red ears of maize (corn) and process them into corn soup and hominy, a food made from soaking kernels in lye or wood ash until they go puffy. Taking the maize from seed to soup is something the Osage have done for centuries. But that tradition has nearly disappeared. "I couldn't hardly find anyone younger than me that had ever done it, even in the most traditional families," he says.

Four years ago, Red Corn was elected assistant chief of the Osage Nation. Right away, he started looking for a spot to plant traditional maize and other crops. Fresh fruit and vegetables are hard to come by in Osage County. Since the 1970s, the Osage people have increasingly relied on canned and processed foods that are high in salt, fat and sugar.

Red Corn wants to see the community take



**"YOU NEVER ASK SOMETHING OF SOMEONE WITHOUT GIVING THEM SOMETHING BACK."**

back control of its food supply. By restoring their connection to the land and its lost food traditions, he thinks, they just might be able to rewind to a healthier lifestyle. The efforts might even help to tackle the high rates of obesity and diabetes in Native Americans in the area. In the Osage Nation, "everything we do revolves around food," Red Corn says. "You can't heal the community unless you heal the food system."

Red Corn and other tribal leaders hoped that providing locally grown fresh foods would yield obvious health benefits, but they weren't equipped to measure those benefits themselves. So, they reached out to Jernigan at the University of Oklahoma Health Sciences Center, who

is a member of the Choctaw Nation. Jernigan has spent the bulk of her career testing strategies to improve the food environment on reservations as a way to enhance health. She has another project with two other Native American communities in Oklahoma to get healthier foods into their convenience stores.

Research on marginalized groups can be fraught, and working with tribal communities is especially complicated. A history of research abuses has left many Native Americans



Researchers excavate an ancient cattle pen for the Morembe Archaeological Project.

mistrustful of the scientific enterprise. In the past, investigators have used tribal members as unwitting participants in unethical and dangerous experiments. And, as in the Havasupai case, scientists have at times withheld information from the communities they have studied and largely ignored tribal concerns.

When Native Americans think of health studies, they often think of "helicopter researchers", Jernigan says — scientists who fly in, collect data and blood samples, and then leave. "And they never see one benefit." What's more, working with indigenous communities means dealing with sovereign governments, some of which have their own institutional review boards. "You have to go through all these extra layers of protections," Jernigan says. These days, collaboration and co-production aren't just ethical, they are mandatory. "There's almost no other way of doing it," she says.

As a first step, Jernigan proposed launching a pilot study to work out what the community actually wanted. The team surveyed everyone from community members to leadership, and found that people seemed most interested in the idea of community gardening. They wanted to use locally grown crops to help supply some of the tribally run programmes for children and older people.

But boosting the supply of fresh fruit and vegetables is only half the battle; people also wanted to increase the desire for healthy foods. So Jernigan worked with the Osage to design a community programme aimed at getting young children and their families to eat more fruit and vegetables. The trial, called Food Resource Equity and Sustainability for Health, or FRESH, launched in January. The team came up with new, healthier menus for a programme that provides care for children aged 3–5 from low-income backgrounds. The researchers also provided the schools with demonstration gardens. Each week, the teachers spend 90 minutes talking stories about food, working with the children in the garden, and conducting a simple cooking lesson. On Fridays, the children take home a healthy meal kit to prepare with their families. Meanwhile, their parents take part in a 15-week online workshop.

The cultural elements are important. Parents are encouraged to attend a monthly family night, where they talk about foods they remember eating when they were young, what they eat now, where it comes from and why they choose certain foods. Jernigan's team has given video cameras to families to record their own food stories. "There's a lot of realization about ▶



## Science shared

Those who were once the subjects of scientific enquiry are increasingly in the driver's seat. A special issue explores the co-production of research.

From people with HIV selecting which trials of antiviral therapies get funded, to farmers of smallholdings guiding weather monitoring, the people affected by research are increasingly getting involved in it. They are helping their projects are conceived, supported, done, assessed, disseminated and rated. They are partners in research production.

This special issue looks at the promise and the pitfalls of co-production for the stakeholders, scientists and societies now working shoulder to shoulder. As one advocate describes it: "It's about getting everybody round the table so you're valuing the knowledge everybody has."

A series of case studies on page 21 illustrates the many forms such research can take. They include a public-health researcher who has been working to curb childhood obesity with members of the Osage Nation, a Native American community in Oklahoma, and climate modellers embedded with city planners in nine southern African cities to help determine the research and infrastructure needed to adapt to climate change. The stories highlight common themes: co-production takes people out of their comfort zones, but the payoff comes in the form of enhanced trust

and communication. Importantly, the research has a much better chance of making a difference to the people involved.

Those who were previously outside the academic system are also becoming gatekeepers for research, helping to decide what gets funded, published and evaluated. A collection of Comment articles describes how patients and carers are invited to review manuscripts at the BMJ (see page 30) and grant applications at the California Institute for Regenerative Medicine (see page 31). In some cases, they encourage risk-taking, in others, they rein in false hope. Another article calls for the wider use of co-created evaluation tools to improve and incentivise research co-production (see page 32).

So how do you join the revolution? Public-involvement manager Gary Hickey offers five principles for co-producing research on page 29. Chief among these is to share power. But, as he writes, co-production won't happen just because everybody around the table is worthwhile, but it takes work.

## COMMENT

**INTELLI** Patients, farmers and more must co-create tools to evaluate and incentivise use **37** **INTELLI** The rise of Reddit social software or social malware? **38** **INTELLI** The interplay of minerals security and US foreign policy **39** **OPEN ACCESS** Playful documentary films screen on Plan Islands **37**



Children with artificial limbs and their carers talk to researchers and industry representatives about improving prosthetics.

## Co-production from proposal to paper

Three examples show how public participation in research can be extended at every step of the process to generate useful knowledge.

### GARY HICKEY Share power in five ways

Senior public-involvement manager at INVOLVE, a UK health-research advisory group

A project that is co-produced is one in which researchers, practitioners and the public together share power and

responsibility for the work throughout. The 'why' of this process are self-evident: patients and the public have the right to be more than just participants in research, and their involvement can lead to better outcomes.

Take for example, the Child Priorities Research Collaboration. This project brought together children and their families with the National Health Service, industry and academia, and was funded by the UK National Institute for Health Research (NIHR). It led to innovation and optimism that reflected what children and families need. The experts and academics who develop prosthetics would probably never have heard from families and children how a poor fitting or unattractive limb can limit a child at home, in the classroom and in the playground.

The 'how' of co-production is less obvious. For the past two and a half years, I have worked with colleagues from the NIHR and beyond to develop guidance

"A project that is **co-produced** is one in which researchers, practitioners and the public together share power and responsibility for the work throughout. The 'whys' of this process are self-evident: patients and the public have the right to be more than just participants in research, and their involvement can lead to better outcomes."

## From INVOLVE, UK health-research advisory group

Editorial/Special issue 2018. Nature 562 <https://www.nature.com/articles/d41586-018-06859-3>



“Bold missions can provide new syntheses that are today impossible and thus will hopefully achieve the breakthroughs that are urgently needed **to solve some of the most pressing issues facing our citizens.**”

“**Citizens** can possibly be mobilised to become **active participants in missions**, for example by cleaning plastics from beaches or by providing real-time monitoring data as enabling technologies develop and become more universally present in society.”



<https://doi.org/10.2777/36546>



# Què és la ciència ciutadana?

12/9/2021

Living bird. - 7 (Illustration, Text)

## CITIZEN SCIENCE *A Lab Tradition*

BY RICK BONNEY

The history of ornithology is replete with the contributions of amateurs. From the early 1800s, when a Scottish poet named Alexander Wilson published the first comprehensive account of North American birdlife, to the turn of the century, as the Audubon Christmas Bird Counts were born, to the present time, as thousands of birders participate in bird censuses, surveys, and research projects across the continent, amateurs have gathered a treasure house of information on bird numbers, bird movements, even basic bird biology.

The Cornell Lab of Ornithology has played a major role in this tradition. In 1929 our founder, Arthur A. Allen, began soliciting bird watchers' sightings to construct a comprehensive database of the birds of central New York's Cayuga Lake Basin. Our Nest Record Program, begun in 1965, was one of the first North American projects to seek amateur-collected data in an organized fashion. Project FeederWatch, which started in 1987, is one of the largest amateur-based data collection programs under way today. And FeederWatch is now joined by several other Lab citizen-science projects, including Project Tanager, Project Pigeon-Watch, and the Cornell Nest Box Network.

It's safe to say that the Lab of Ornithology depends on amateurs to collect data. But citizen science is a two-way street. Participants gain from the projects, too. From backyard birders to school children, amateur ornithologists become proficient in bird identification, acquire the skills of par-

tient observation, imbibe the process of scientific investigation, and gain the satisfaction of furthering scientific knowledge.

The Lab also hopes that public participation in bird studies will spawn action on behalf of birds. As project participants evolve from birders to citizen scientists, we hope they'll go to work on behalf of birds. Our goal? That bird watchers will save the world.

The next few pages present an overview of the Lab's many citizen-science projects. ■

*By contributing data on bird numbers and behavior on a continentwide scale, the Lab's "Citizen Scientists" make a real contribution to bird conservation. Here two Cornell Nest Box Network participants check the contents of a Tree Swallow nest.*

For more information on any of our citizen-science projects, contact: Education Program, Cornell Lab of Ornithology, 159 Sapsucker Woods Road, Ithaca, New York 14850; telephone: (607)254-2440; e-mail: birdeducation@cornell.edu; or visit our web site (<http://www.ornith.cornell.edu>).

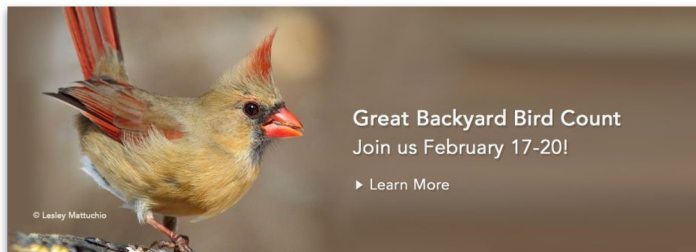


Autumn 1996. 7

Bonney R. 1996. Citizen science: a lab tradition. *Living Bird* 15, 7-15.  
Accessible a: <https://www.biodiversitylibrary.org>



# Què és la ciència ciutadana?



The Cornell Lab of Ornithology  
Exploring and Conserving Nature

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About Us What We Do Give All About Birds Find

Mission: Citizen Science

What We Do  
 Research  
 Education  
 Citizen Science  
 Technology  
 Conservation  
 Lab Programs

How YOU CAN HELP

We rely on your support to further our mission to understand birds and other wildlife, to involve the public in scientific discovery, and to use our knowledge to protect our planet.

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Scientific Papers  
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**Citizen Science**

Hundreds of thousands of people around the world contribute bird observations to the Cornell Lab each year, gathering data on a scale once unimaginable. Scientists use these data to determine how birds are affected by habitat loss, pollution, disease, and climate change. They trace bird migration and document long-term changes in bird numbers, creating species-specific conservation plans and targeted action to help birds find the resources they need to survive.

If you enjoy watching birds, consider harnessing your passion for conservation, whether that be watching birds at your feeders during the winter, monitoring birds in the nest, or sharing your checklists anytime, anywhere through eBird. You'll be most welcome in our birding community!

**Project Highlights**

Projects at a Glance Citizen-Science Results Citizen-Science Technology

**QUICK FACTS**

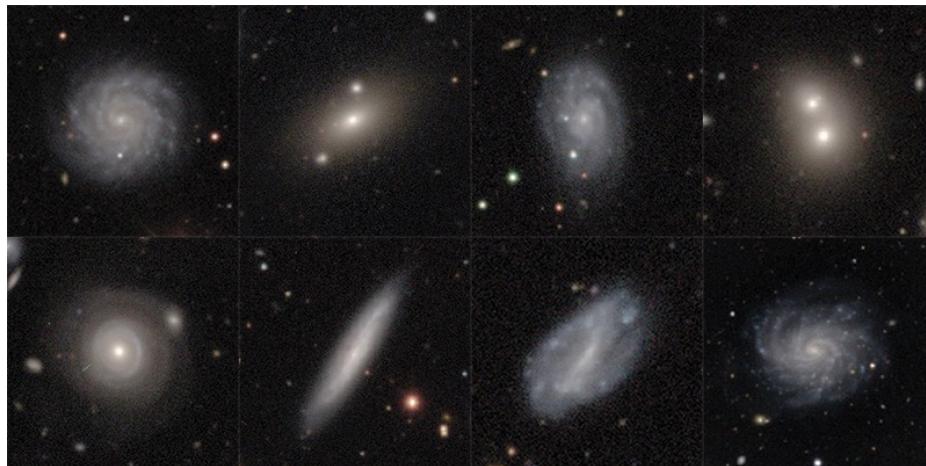
- At least 150 scientific papers have used Cornell Lab citizen-science data since 1997.
- More than 300,000 nesting attempts reported to the Cornell Lab since 1997.
- More than 7.5 million bird observations reported to eBird on average each month.

<https://www.birds.cornell.edu/home/>

<http://www.cornell.edu/video/ebird-migration-animation>

# Què és la ciència ciutadana?

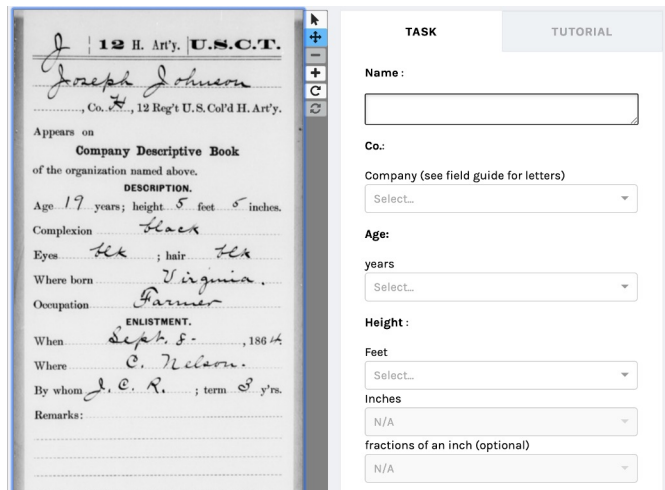
“Welcome to **Galaxy Zoo**'s latest incarnation. For more than a decade, we've asked volunteers to help us explore galaxies near and far, sampling a fraction of the roughly one hundred billion that are scattered throughout the observable Universe.”



<https://www.zooniverse.org/projects/zookeeper/galaxy-zoo/>

# Què és la ciència ciutadana?

“**Crowd-sourcing transcription project** is a collaboration between historians, social scientists and the African American Civil War Museum. To improve our knowledge of the African Americans who fought for freedom in the American Civil War.”



**12 H. Art'y. U.S.C.T.**  
*Joseph Johnson*  
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Appears on  
**Company Descriptive Book**  
 of the organization named above.

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 Where born *Virginia*  
 Occupation *Farmer*

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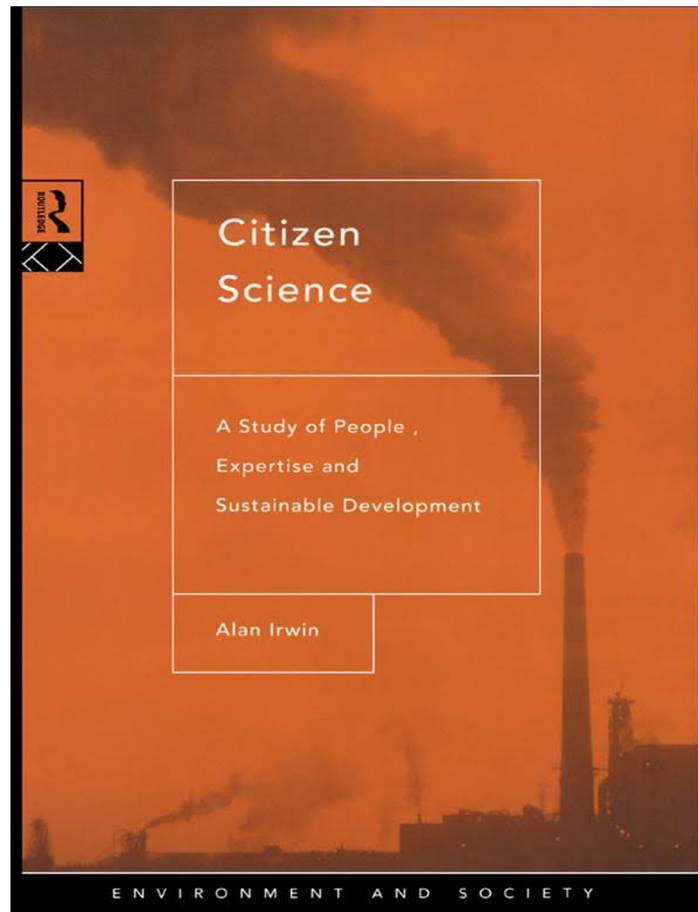
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<https://www.zooniverse.org/>

“Zooniverse: People powered research”

Gran col·lecció de projectes

# Què és la ciència ciutadana?



Irwin, A. (1995). Citizen science: A study of people, expertise and sustainable development. Routledge Press.

# Què és la ciència ciutadana?

“La ciència (ciutadana) hauria de respondre a les inquietuds i necessitats dels ciutadans.

[...]

Els ciutadans poden produir un coneixement científic fiable.”

Alan Irwin, Investigador en Ciències Socials, Copenhagen Business School. Un dels introductors del terme **ciència ciutadana**. El llibre: Citizen Science: A Study of People, Expertise and Sustainable Development (1995)

# Què és la ciència ciutadana?

## Citizen Science - A book

Vohland, K., Land-Zandstra, A., Ceccaroni, L., Lemmens, R., Perelló, J., Ponti, M., ... & Wagenknecht, K. (2021). The science of citizen science (p. 529).

Springer


<https://doi.org/10.1007/978-3-030-58278-4>

Katrin Vohland · Anne Land-Zandstra  
Luigi Ceccaroni · Rob Lemmens  
Josep Perelló · Marisa Ponti  
Roeland Samson · Katherin Wagenknecht  
*Editors*

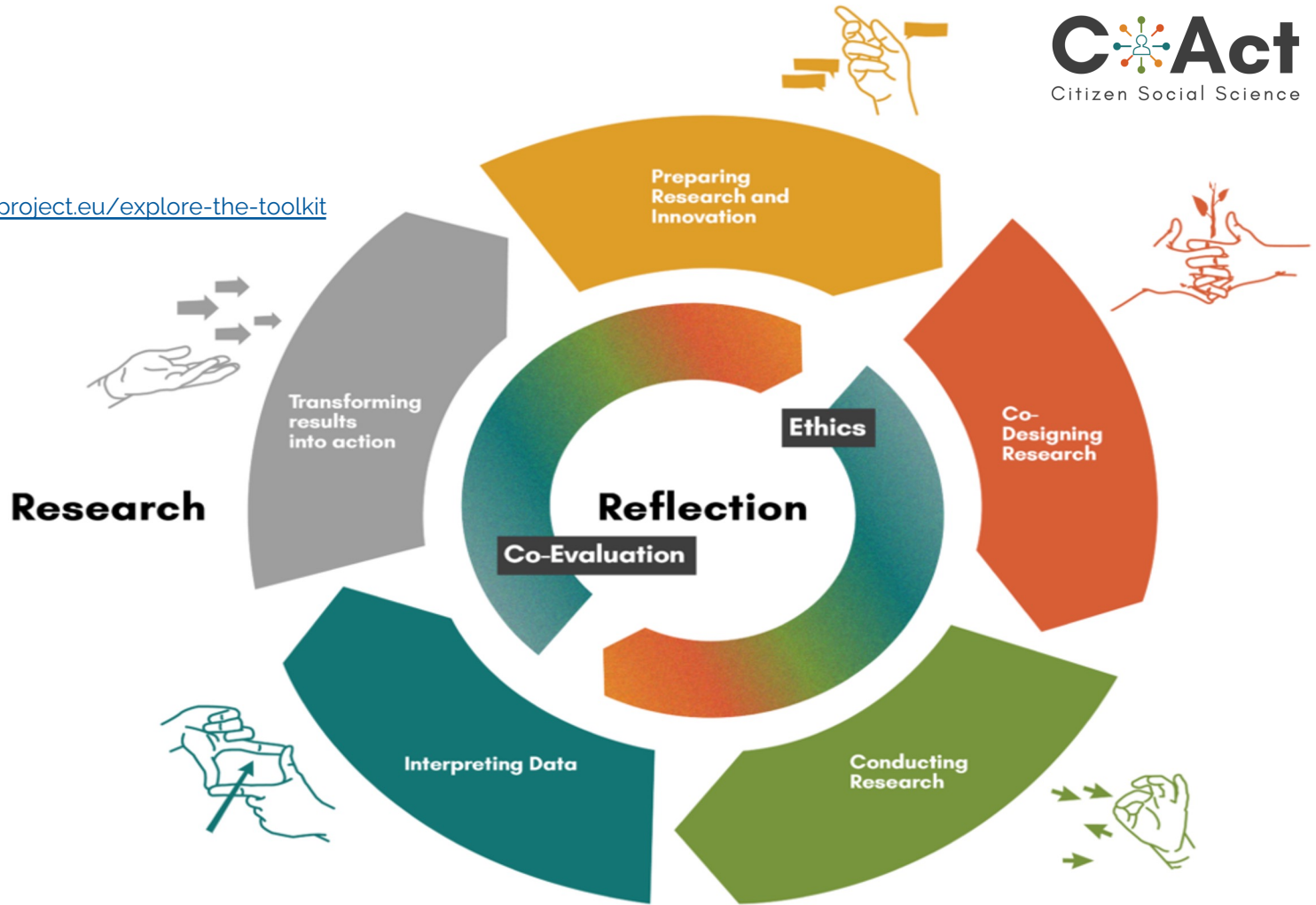
# The Science of Citizen Science



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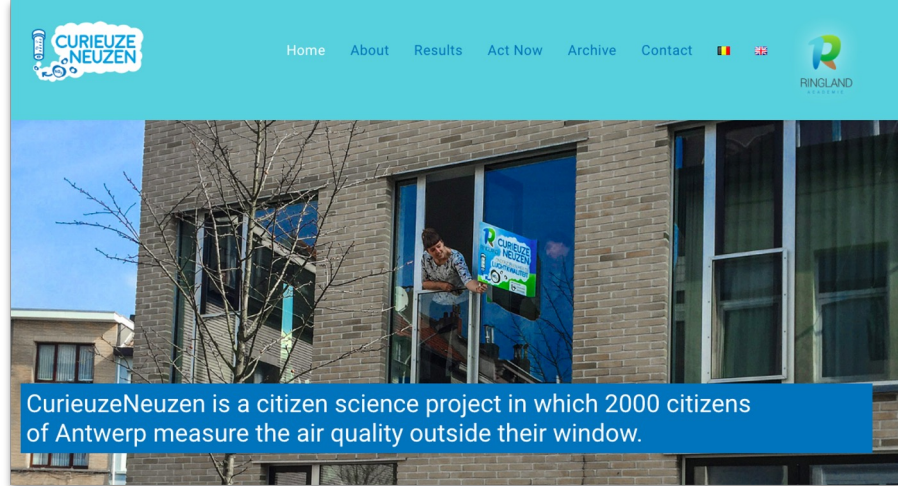
 Springer

CoAct Toolkit. <https://coactproject.eu/explore-the-toolkit>





Flint Water Crisis. LeeAnne Walters  
Credit: Ryan Garza/Detroit Free Press via ZUMA



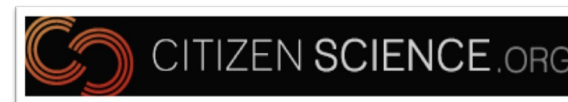
<https://curieuzeneuzen.be>



# Marcos i contextos d'actuació



<https://ecsa.citizen-science.net>



<https://citizenscience.org>



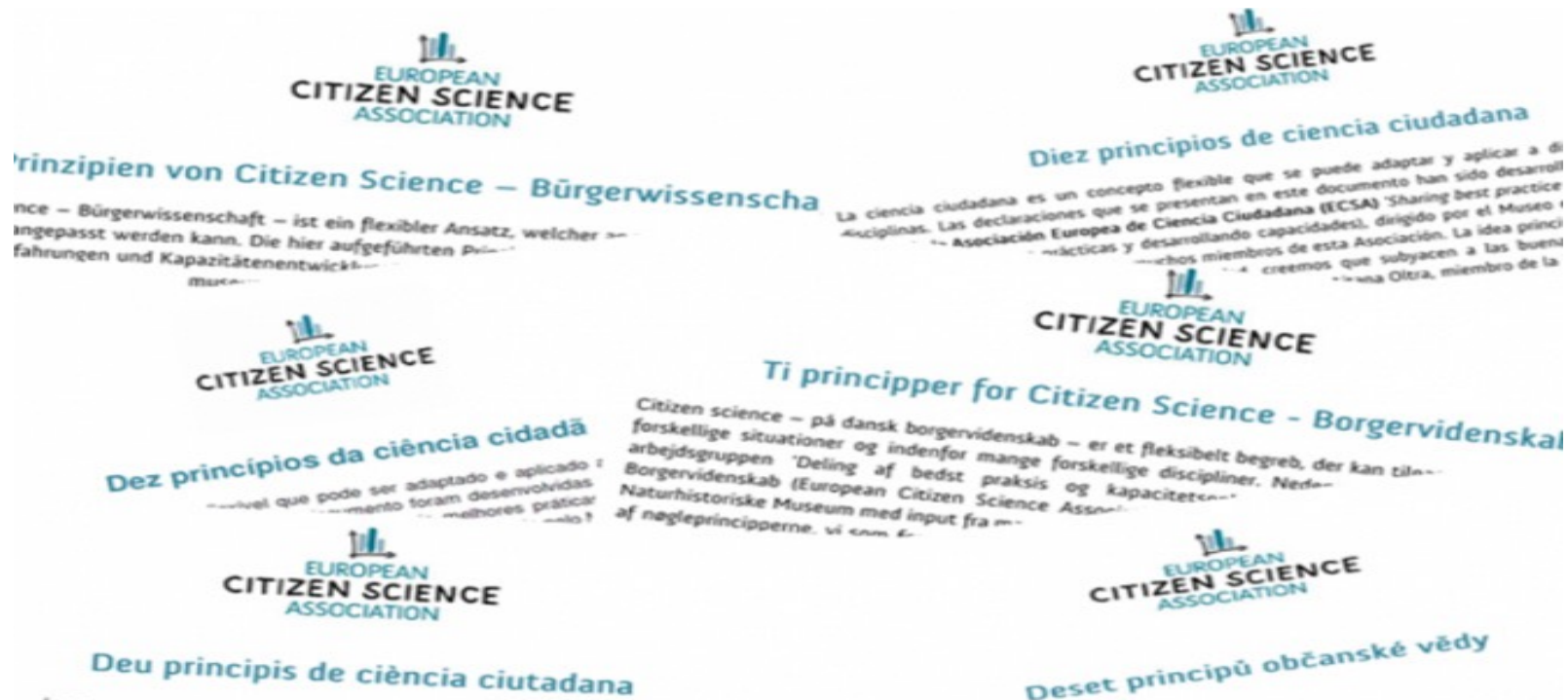
<https://ciencia-ciudadana.es>



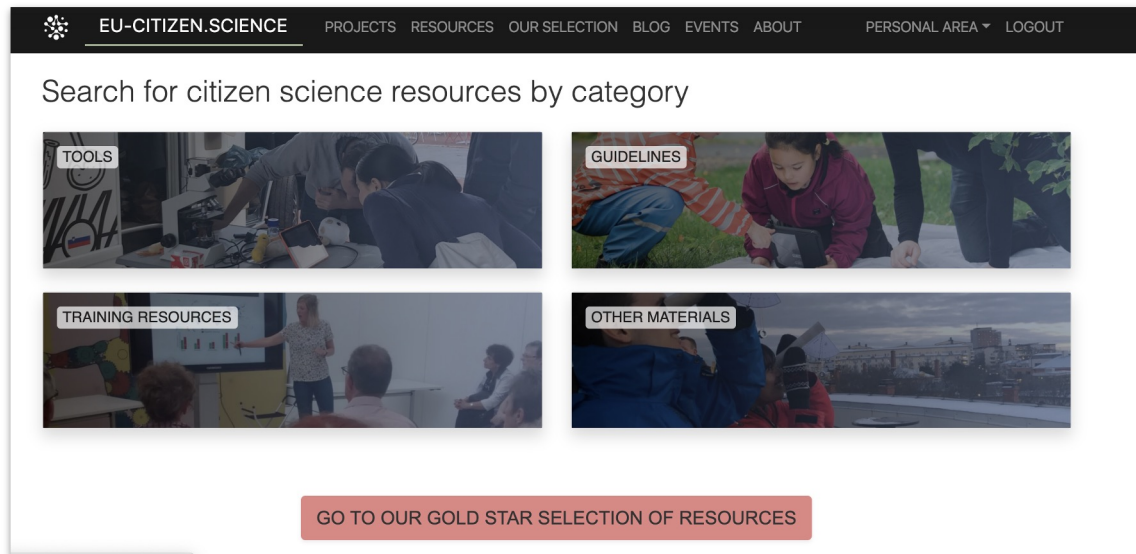
<https://www.barcelona.cat/barcelonaciencia/es/ciencia-ciudadana>

# Marc i contextos d'actuació

2015: 10 principis de la ciència ciutadana (ECSA)



## EU-Citizen.Science



The screenshot shows the website's navigation bar with the following items: EU-CITIZEN.SCIENCE, PROJECTS, RESOURCES, OUR SELECTION, BLOG, EVENTS, ABOUT, PERSONAL AREA, and LOGOUT. Below the navigation bar, there is a search prompt: "Search for citizen science resources by category". Four category tiles are displayed in a 2x2 grid:

- TOOLS**: Image showing people working at a computer workstation.
- GUIDELINES**: Image showing a person in a red jacket looking at a tablet outdoors.
- TRAINING RESOURCES**: Image showing a person presenting to a group in a classroom.
- OTHER MATERIALS**: Image showing a person looking through a telescope on a rooftop.

At the bottom of the grid is a red button with the text: "GO TO OUR GOLD STAR SELECTION OF RESOURCES".

The ambition of EU-Citizen.Science is to build, fill, and promote a sustainable platform and mutual learning space providing different tools, practice examples and scientific outcomes.

[EU-Citizen.Science](https://eu-citizen.science)

# Marc i contextos d'actuació



OFICINA  
CIÈNCIA CIUTADANA  
BARCELONA

L'Oficina neix el 2012 impulsada per l'Institut de Cultura de l'Ajuntament de Barcelona amb la voluntat de consolidar els projectes de ciència ciutadana existents, acompanyar-los i crear un espai d'aprenentatge comú per a noves iniciatives.

[Oficina de Ciència Ciutadana | Barcelona Ciència](#)

# Marc i contextos d'actuació

## Ciència Ciutadana i Aprenentatge Servei

L'aprenentatge servei és una proposta educativa que combina l'ús i l'adquisició de coneixements amb la realització d'un servei útil a la comunitat. Els participants es formen tot treballant sobre problemes reals amb la intenció de fer aportacions positives a la societat.



[https://aprenentatgeservei.cat/wp-content/uploads/quaderns\\_aps/cat\\_CC-I-APS-def.pdf](https://aprenentatgeservei.cat/wp-content/uploads/quaderns_aps/cat_CC-I-APS-def.pdf)

# Marcos i contextos d'actuació

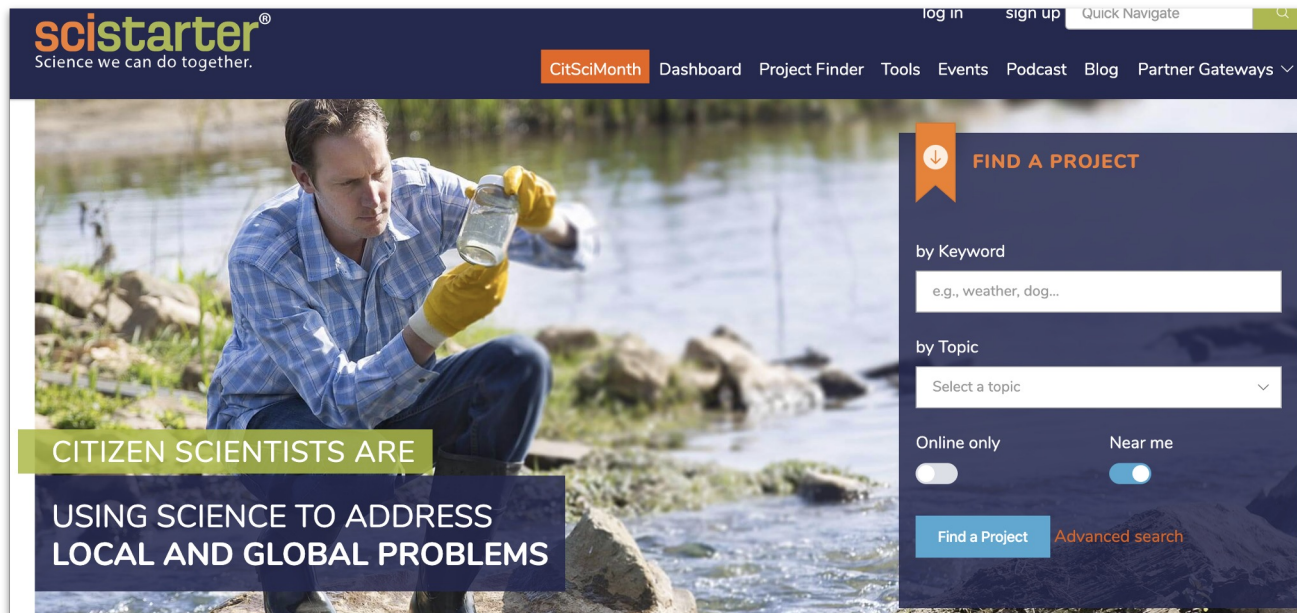


## Observatorio de la Ciencia Ciudadana

“Buscamos facilitar el conocimiento de esta metodología científica.”

<https://ciencia-ciudadana.es>

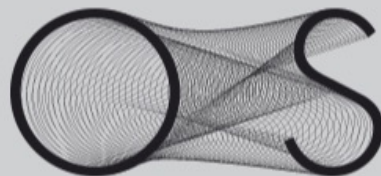
# Marc i contextos d'actuació



Scistarter, USA. <https://scistarter.org>



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**CAP A UNA PRÀCTICA MULTIDISCIPLINÀRIA ON ART I  
PARTICIPACIÓ CIUTADANA SIGUIN PART FONDAMENTAL  
EN LA MANERA DE FER CIÈNCIA.**







StemforYouth. Athens (Palaio Faliro) 2017  
Collective behavioural experiment of Environmental Coastal Pollution



StemforYouth. Viladecans 2017

Senabre, E., Ferran-Ferrer, N., & Perelló, J. (2018). Participatory design of citizen science experiments. *Comunicar*, 26(54), 29-38. <https://doi.org/10.3916/C54-2018-03>

# CIÈNCIA CIUTADANA A LES BIBLIOTEQUES

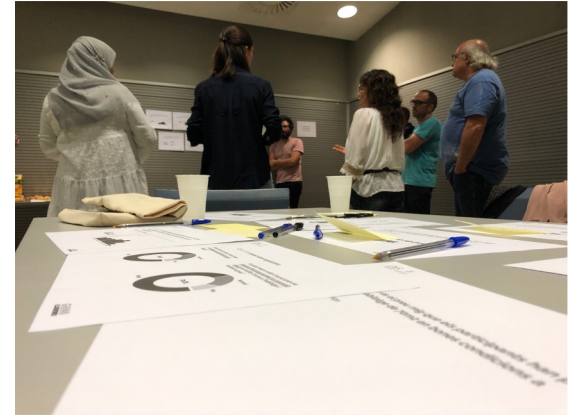
## OBSERVA, ANALITZA, CREA I PARTICIPA

OpenSystems



<https://zenodo.org/record/3490610#.XqGc1xMzafU>

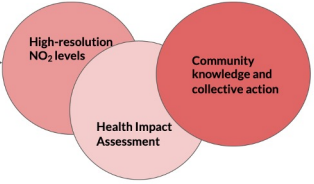
Cigarini, A., Bonhoure, I., Vicens, J., & Perelló, J. (2021). Public libraries embrace citizen science: Strengths and challenges. *Library & Information Science Research*, 43(2), 101090. <https://doi.org/10.1016/j.lisr.2021.101090>



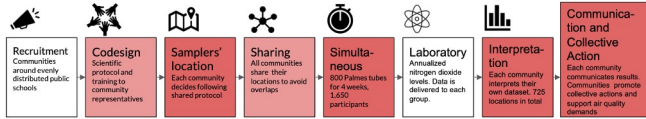
Context and inception



Large-scale citizen science campaign outputs



Participatory research process



air/aria/aire  
Catalonia  
in Venice

Perelló, J., Cigarini, A., Vicens, J., Bonhoure, I., Rojas-Rueda, D., Nieuwenhuijsen, M. J., ... & Ripoll, A. (2021). Large-scale citizen science provides high-resolution nitrogen dioxide values and health impact while enhancing community knowledge and collective action. *Science of The Total Environment*, 789, 147750. <https://doi.org/10.1016/j.scitotenv.2021.147750>

## Urgent Estimar

FiraTàrrrega. Tàrrrega, September 2017. Ada Vilaró & Josep Perelló & OpenSystems

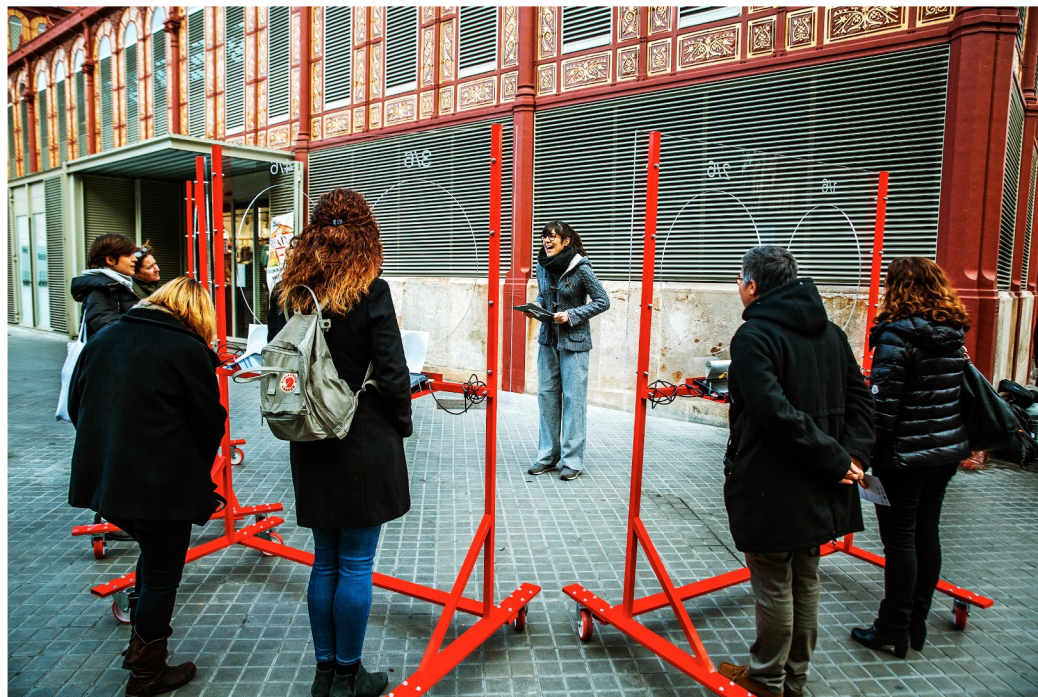


Cigarini, A., Vicens, J. & Perelló, J. Gender-based pairings influence cooperative expectations and behaviours. *Sci Rep* 10, 1041 (2020).

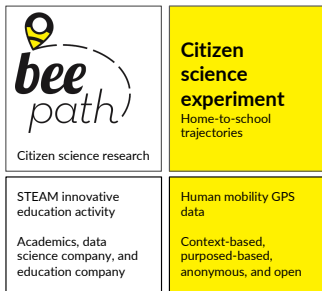
<https://doi.org/10.1038/s41598-020-57749-6>

## ConSCIÈNCIES a la plaça.

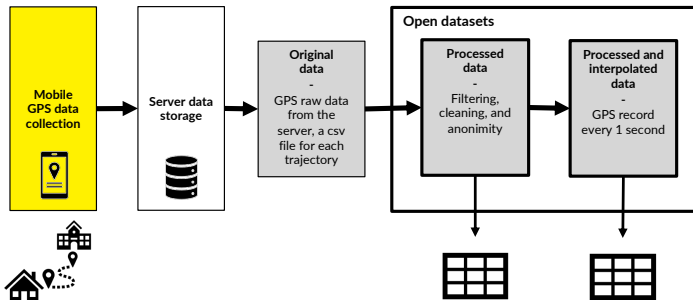
Violències de gènere a l'espai públic. Biennial Ciutat i Ciència 2019. Amb Ajuntament de Barcelona, municipality, NUS Teatre i Elisava



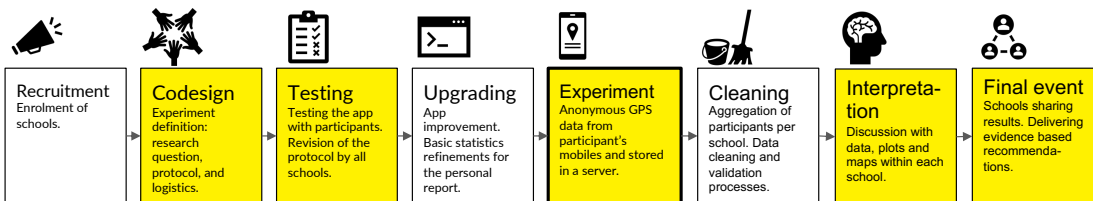
### Concept and context



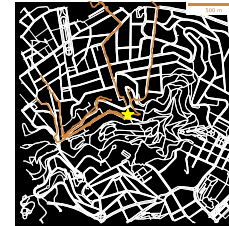
### Human mobility data – Home to school pedestrian mobility data



### Participatory research process



(a)



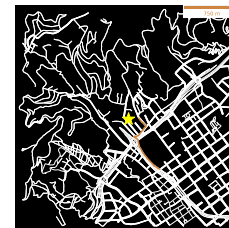
(b)



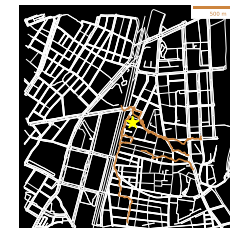
(c)



(d)



(e)



(f)



(g)



(h)



(i)



(j)

# Estenent la dimensió social de la ciència ciutadana

## Ciència ciutadana social

Recerca participativa co-dissenyada i impulsada directament per grups de ciutadans que comparteixen una preocupació social.



www.thinkdoodly.com 2019



# Estenent la dimensió social de la ciència ciutadana

## Persones Coinvestigadores

Tenen una experiència viscuda en relació a les preocupacions socials i, per tant, reconegudes com a experts en la matèria.





## Reptes

Coproducció / Aprenentatges

Vivències / Expertesa

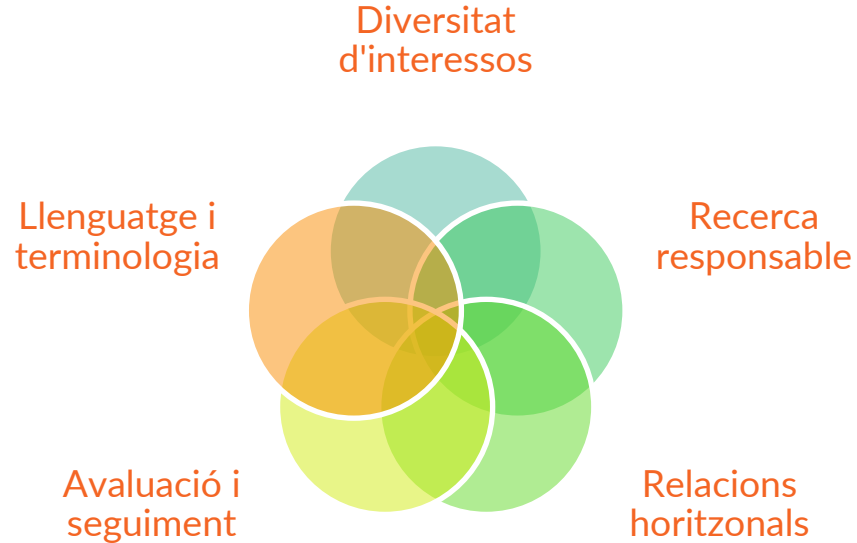
Coneixement / Acció basada en evidències



Albert, A., Balázs, B., Butkevičienė, E., Mayer, K., & Perelló, J. (2021). Citizen social science: new and established approaches to participation in social research. Chapter 7. In: Vohland K. et al.(Eds). 2021. The Science of Citizen Science. Springer. <https://doi.org/10.1007/978-3-030-58278-4>. pp: 119-138.



## Reptes



Albert, A., Balázs, B., Butkevičienė, E., Mayer, K., & Perelló, J. (2021). Citizen social science: new and established approaches to participation in social research. Chapter 7. In: Vohland K. et al.(Eds). 2021. The Science of Citizen Science. Springer.  
<https://doi.org/10.1007/978-3-030-58278-4>. pp: 119-138.

Irwin, A (2018). Citizen Science Comes of Age. Nature, 562(7728), 480-482. <https://doi.org/10.1038/d41586-018-07106-5>

- Institucionalització i Formació
- Mètodes / Protocols
- Dimensió social
- Coneixement accionable
- Replicabilitat
- Escalabilitat
- Actors implicats
- Ubicacions i contextos
- Col·lectius en situació de vulnerabilitat
- Part d'una democràcia deliberativa
- Enfocament (in)disciplinari



# CITIZEN SCIENCE COMES OF AGE

*Efforts to engage the public in research are bigger and more diverse than ever. But how much more room is there to grow?*

BY AISLING IRWIN

**F**lip Meysman knew he had made his mark on Antwerp when he overheard commuters discussing his research project on the train. Then, just a few days later, he saw an advertisement about his work on television. There it was, he says, "in between the toothpaste and George Clooney's Nespresso".

As a biogeochemist at the University of Antwerp in Belgium, Meysman wasn't used to drawing so much attention. But that was before he adopted the citizens of northern Belgium as research partners. With the help of the Flemish environmental protection agency and a regional newspaper, Meysman and a team of non-academics attracted more than 50,000 people to Curieuzeneuzen, an effort to assess the region's air quality (the name is a play on Antwerp dialect for 'nosy' people).

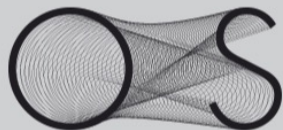
The project ultimately distributed air-pollution samplers to 20,000 participants, who took readings for a month (see 'Street science'). More than 99% of the sensors were returned to Meysman's laboratory for analysis, yielding a bounty of 17,800 data points. They provided Meysman and his colleagues with information about nitrogen dioxide concentrations at 'nose height' — a level of the atmosphere that can't be discerned by satellite and would be prohibitively expensive for scientists to measure on their own. "It has given us a data set which it is not possible to get by other means," says Meysman, who models air quality.

Citizen science — active public involvement in scientific research — is growing bigger, more ambitious and more networked. Beyond monitoring pollution and snapping millions of pictures of flora and fauna, people are building Geiger counters to assess radiation levels, photographing stagnant water to help document the spread of mosquito-borne disease, and taking videos of water flow to calibrate flood models. And an increasing number are donating thinking time to help speed up meta-analyses or assess images in ways that algorithms cannot yet match.

The movement is surging wider societal forces, including a thirst for data; the rise of connectedness and low-cost sensor technologies; and a push to improve the transparency and accessibility of science. Increasingly, government institutions and international organizations are getting in on the action. The US and Scottish environmental protection agencies, for example, have incorporated citizen science in their routine work. The United Nations Environment Programme is exploring ways of using citizen science to both monitor the environment and stoke environmental concern. And the European Commission has made a range of funding opportunities available for citizen science within its €80-billion

Japanese priest Sadamaru Okano stands beneath a Geiger counter (top left) that sends radiation readings to the Safecast project.

BERNARD MERRIFIELD



**CAP A UNA PRÀCTICA MULTIDISCIPLINÀRIA ON ART I PARTICIPACIÓ CIUTADANA SIGUIN PART FONAMENTAL EN LA MANERA DE FER CIÈNCIA.**

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