

ANNALS OF THE NEW YORK ACADEMY OF SCIENCES

Special Issue: *The Year in Ecology and Conservation Biology*

REVIEW

Citizen science in ecology: a place for humans in natureFrederick R. Adler,^{1,2,a}  Austin M. Green,^{1,a} and Çağan H. Şekercioğlu^{1,3,4}¹School of Biological Sciences, University of Utah, Salt Lake City, Utah. ²Department of Mathematics, University of Utah, Salt Lake City, Utah. ³Conservation Science Group, Department of Zoology, Cambridge University, Cambridge, United Kingdom.⁴Department of Molecular Biology and Genetics, Koç University, Istanbul, TurkeyAddress for correspondence: Frederick R. Adler, School of Biological Sciences, University of Utah, Salt Lake City, UT 84112. adler@math.utah.edu

By involving the public, citizen science runs against the grain of an idealized science that leaves out the human element, and thus provides new opportunities for ecological research and society. We classify the goals of citizen science in ecology and environment into four broad categories: (1) scientific, (2) participant benefits, (3) community, and (4) policy. Although none of these goals have been well studied, we review the literature showing that these projects are most effective in tracking ecological trends over large swaths of space and time, and discuss the challenges of recruiting, training, retaining, and educating participants, maintaining and disseminating high-quality data, and connecting with the larger community and policy. Biomedical studies, where patients participate in their own treatment in randomized trials, provide an interesting comparison with citizen science in ecology, sharing challenges in recruitment and involvement of nonscientists and ethical conduct of research. Future study will help address the ethical difficulties and enhance ways for citizen science in ecology and the environment to complement scientific discovery, involve and educate the public, and guide policy founded in science and the local community.

Keywords: citizen science; biomedical science; ecology; environment

Introduction

In one ideal, science seeks as much as possible to remove the human element. Objectivity seeks to remove both values and preconceptions.¹ The textbook version of hypothesis testing ignores the serendipity of observation and buries the human and societal biases in the questions we choose to ask.² The scientist, like Dr. Frankenstein, works alone, turning to others as a respite from the rigors of investigation.³ Experts turn to nonexperts only as assistants, not as collaborators who could understand seemingly esoteric knowledge.⁴ In this ideal, studies of ecology seek out pristine nature, untouched by humans, to reveal the complex processes that shape the world around us. And the quest for truth should in no way be sullied by policy considerations or be confused with any sort of advocacy.

This ideal, of course, has never existed, but it has been challenged by many currents in recent times.⁵ The rise of citizen science exemplifies many of these currents and breaks down every aspect of the inhuman ideal caricatured above. By definition, the scientist cannot work alone, and turns to others not for emotional support but for scientific assistance and insight into the larger implications of the research. The quest for truth is thus coupled with many other goals, including educating and involving people from diverse backgrounds, and treating those people ethically and respectfully. Many studies are observational, such as tracking the distribution and abundance of organisms, rather than testing a hypothesis, and the questions to be studied may arise not from the internal logic of scientific progress but from the concerns of participants. People live near other people and are concerned about the changes in the world we have created; citizen scientists have little access to the supposedly pristine. Finally, many, if not most, people who engage in ecological research do so precisely because of

^aBoth the authors contributed equally.

its policy implications and to advocate for specific actions.⁶

Scientists and citizens who engage in ecological and environmental research sometimes conceptualize these policy concerns in terms of health: diagnosing and restoring an ecosystem.^{7,8} In the context of biomedical research, this parallel is more than a metaphor.⁹ Diagnosis and treatment in medicine require the participation of patients and their families, and the underlying science is built on medical research involving patient volunteers. In this paper, we use the commonalities and contrasts with biomedical research to cast new light on the assumptions we make about citizen science in ecology and the environment.

Clinical research cannot be done without people, that is, patients, making the isolated ideal not only impossible but also absurd. This creates a series of ethical challenges addressed through best practices, such as informed consent. The high personal stakes for critically ill patients and their families place them in a position to shape research questions, a direction taken only rarely and recently. Both medical and ecological studies must find ways to recruit participants, share results, and maintain ethical standards. The challenges of ownership of data collected by citizen scientists have even higher stakes with patient data and samples taken from patients, as exemplified by the effectively immortal cells taken from cancer patient Henrietta Lacks without her knowledge.¹⁰ Because the goal of good health is universally accepted, there is little contention about crossing the line from science to advocacy. This universal agreement, however, breaks down when balancing between goals, such as duration and quality of life, or in goals where subjective values, like appearance, affect recommendations about losing weight.

This review presents an overview of citizen science, primarily in ecology and conservation biology, framed by this perspective; citizen science fundamentally changes the way in which we conceptualize and engage in the scientific enterprise. We begin by summarizing the goals and scope of citizen science investigations, along with some of their successes and challenges, integrate with the analogy of biomedical research involving patients, and conclude with open areas of opportunity. Although this is not a systematic review of citizen science in the fields of ecology and biomedical

research, we aim to provide an up-to-date synthesis of each, a novel perspective on how they are related, and a spur to future research to address knowledge gaps and critical challenges.

An overview of citizen science

The expansion of citizen science has resulted not only from changing views of science, but also from more pragmatic factors, primarily the rise of internet technologies that make data collection and sharing at large scales far more efficient, and because citizen scientists work as volunteers at low cost and sometimes with separate funding streams.¹¹

Citizen science projects have been categorized in many ways, depending on the approach, goals, or system. For example, Bonney¹² describes four categories: data collection, data processing, curriculum based, and community science. We here focus on the first of these goals, those where data are collected in the field, but potentially with multiple and sometimes conflicting goals.^{13,14} We classify citizen science data collection goals into four broad categories: (1) scientific, (2) participant benefits, (3) community, and (4) policy. For studies with significant data collection, we elaborate on the challenges of designing, implementing, sustaining, and following up the process^{15–17} so that future practitioners can make more informed decisions.

Scientific goals

Among scientific goals, citizen science is particularly effective at addressing ecological questions at large spatial and temporal scales that cannot be covered by a small team of investigators.^{18,19} By tracking ecosystems over time, citizen science can provide crucial baseline information on effects of global change²⁰ and for identifying locations with both good and poor environmental health.¹⁹

Because citizen science projects can last far longer than any particular individual effort and cover far more ground, they are particularly effective in mapping the spatial distribution of species, their declines or increases,²¹ changes in species distribution as a result of climate change,^{22,23} and the spread of biological invasions at scales not attainable through more traditional methods.^{24–26} Although less focused on hypothesis testing, citizen science is effective at large-scale studies of habitat loss, range, and phenology shifts,²⁴ and for tracking infectious disease and invasive species over large

areas and long temporal extents.^{27,28} For example, citizen science has helped in studying kissing bugs, *Triatominae*, to assess the entomological risk of Chagas disease in Texas.²⁹

Even when citizen science studies are not maintained continuously over long periods of time, the power to link long-term studies to historical amateur naturalist datasets can offer an exciting glimpse into the distant past, and modern comparisons provide a novel way of engaging citizen scientists and creating studies that encompass decades or centuries.³⁰ These historical data provide a foundation for assessing species richness and occurrence across a landscape and for measuring the conservation status of rare and elusive species.³¹

For a range of historical and financial reasons, scientific studies often focus on particular sets of organisms, habitats, and regions. Citizen science projects are focused in Europe, North America, South Africa, India, and Australia²⁴ and are rare in many developing countries.¹⁸ Nonetheless, citizen science has contributed to conservation on an international level, and is a burgeoning area of research. The match of citizen science with large-scale studies of species' distribution and population trends lends itself well to international research, as most species' ranges do not follow political boundaries. Therefore, species conservation typically requires international cooperation and both local and regional support. Currently, most of this international work is done by large organizations. For example, the Earthwatch Institute, an international nonprofit organization specializing in ecological, citizen science-based research, has recruited and trained thousands of volunteers to participate in dozens of projects across 30 different countries.³² With over 600 million records, eBird, operated by the Cornell Lab of Ornithology, has become an international sensation for both amateur birding enthusiasts and professional ornithologists. Millions of checklists are uploaded from around the world each day, which is leading to peer-reviewed publications spanning large spatial scales and temporal extents.³³ eBird checklists have been used to assess bird population trends in North America,²¹ with models for species with more than 10,000 uploaded checklists producing population trend estimates consistent with more formal assessments. eBird checklists have also been used to quantify spatiotemporal shifts in migration phenology as a

function of average temperature,^{34,35} while eBird and similar country-level initiatives can provide critical data to model the effects of climate change on the distribution of birds and other organisms.²²

Zooniverse is another collaboration, led by a single large organization, that crosses political boundaries and multiple independent research groups. Nearly, 70 different ecological citizen science projects housed in the Zooniverse span over 50 different countries and all seven continents. eMammal, an online citizen science platform built specifically for camera trapping projects, currently houses 110 different projects from 22 different countries. As is the case in most ecological research, citizen science initiatives are concentrated in developed and temperate countries. Operation Wallacea is one example of a volunteer-funded conservation-and-research organization with a particular focus on the tropics; it focuses primarily on biodiversity monitoring across 14 countries, but also establishes collaborations with biologists with specific research questions.²³ The relatively low number of international citizen science publications resulting from these projects indicates many promising research opportunities.

At a smaller scale, the matrix of private land ownership and political boundaries in urban areas creates challenges for citizen science, because people who have nothing directly to do with the study can interfere with the potentially intrusive aspects of science. Getting private landowners involved in research across a residential matrix remains a challenge,³⁶ but building community through citizen science may offer a way to expand into understudied areas of private land.²⁸

With the large pool of potential participants available in densely populated cities, urban ecosystems have great potential for the creation of citizen science projects. Successful projects include the Tucson Bird Count and Chicago Wildlife Watch.³⁷ The strength of citizen science data in addressing questions in landscape ecology and climate change, as well as finding rare organisms, tracking animal dispersal and distribution, and assessing species population trends, is ripe to expand into urban, agricultural, and residential ecology across a gradient of wildland-urban interfaces.³⁸ For example, citizen scientists can be effective in assessing animal populations on stretches of road not previously documented.³⁹

Participant benefits

The goals of scientists themselves are not restricted to expanding scientific knowledge and recognition, but extend to more human goals of leadership, education, and outreach.⁴⁰ For participants, goals are similarly broad. Involvement in citizen science projects promotes engagement with scientists, learning of both science and the scientific method, and participant well-being.¹² Evaluating the success in reaching these goals, however, remains spotty.^{41,42} One study of aerosols showed that people learn about their specific topic but was less clear whether they learn about the scientific process more broadly.⁴³ Even online-based citizen science, where direct communication with professional scientists and experts is minimal and educational resources may be sparse, has been shown to lead to increases in scientific knowledge, an increase correlated with the amount of time spent contributing to a project.⁴⁴ Teaching the nature of science is difficult, and citizen science programs alone may not be sufficient toward this end, although they can provide a scaffold for creating more in-depth educational programs.⁴⁵

Outside the ecological community, projects have engaged the computer gaming community through challenges like the online protein folding game Foldit, an example of classification through “distributed thinking.”⁴⁶ Foldit has had notable successes, including well-cited studies showing efficient remodeling of an enzyme⁴⁷ and generation of the structure of a retroviral protease after other methods failed.⁴⁸ Reasons for participation parallel those of the ecological studies we focus on, including contribution to and curiosity about science, being part of a community, and the challenge itself.⁴⁶

People join citizen science studies out of the same curiosity that drives scientists,⁴⁶ and nearly 80% of participants in one study engaged in thinking processes resembling that of typical scientific investigation.⁴⁹ As with scientists, motivations to join a project link to many aspects of humanity beyond simple curiosity. For example, people participated in Nestwatch in order to contribute to a scientific study, learn more about birds, and learn about their local environment.⁵⁰

Retaining and engaging participants year after year, even in successful projects, remains difficult. A recent investigation of citizen science contribution tendencies across multiple projects has shown that

a small number of participants, as few as 10%, make the majority of contributions to a project’s total citizen science effort.¹⁵ A similar investigation showed that an overwhelming majority of citizen science participants were classified as “One-Time” or “One-Session” volunteers.⁵¹ Research on factors that motivate volunteers to continue participating in an extended citizen science program has identified interest in the topic, a strong sense of pride, wildlife encounters, and self-interest in gaining research experience.^{16,49,52} Different types of study appeal to different audiences. Parrish *et al.* showed a large discrepancy between citizen science participation between online-based and outdoor-based projects, modified by demographic factors, such as age, experience, and previous participation.¹⁷

Projects that keep participants up-to-date and provide feedback tend to have higher rates of volunteer retention and participation,^{43,53} and building continuity by having volunteers with experience oversee quality control and training can improve retention and participation.⁵⁴ No matter how a citizen science project is sustained from year to year, creating such an institutional framework can benefit from collaboration with experts in people management and volunteer engagement, development of a standardized training program, and using a consistent methodology that does not change drastically through time.⁵⁵

Citizen science has the capability to bring local issues to the global populace, as well as unite people from all over the world under large umbrella programs.³² This has received even less study than its effectiveness in education.⁵⁶ Given this lack of information, scientists who design projects need to think carefully about their goals, and whether and how they include democratization of science.¹² For example, in coral reefs, citizen science research in collaboration with private entities and organizations can help increase volunteer outreach, education, and community-building capacity.⁵⁷ Based on work with Zooniverse, the scientific impact of and public engagement in citizen science projects are tightly correlated, suggesting that investment in one may facilitate the other.⁵⁸

Building community

In addition to learning about science and scientific topics, many people see citizen science as a way to join a community.⁴³ The goal of building

community in general lies well outside the simple discovery goals of science and begins to lean toward policy. Distrust in scientific solutions to environmental problems, especially when those solutions are at cultural or societal odds with the local community, can be overcome in part by bringing communities together.³² Citizen science can thus be effective in bridging the gap between the everyday impacts of policy and the scientific foundations of that policy, particularly when the project focuses on specific aspects of local environmental policy.⁵⁹ This approach addresses two issues: public education about local environmental issues and public engagement in environmental policy planning, implementation, and monitoring, in addition to spreading scientific literacy and the encouragement of environmental stewardship through public conservation action.⁶⁰

Furthering policy

Contributions to policy and management span many areas. Citizen science helps wildlife and resources managers to gather important data in near real time with large publicly available databases.^{35,60} Long-term citizen science studies help document the ecological effects of climate change.^{22,23,42} In fact, long-term monitoring is often the greatest gap in ecological restoration projects, and citizen science, with its lower costs and potential for sustained follow-up, is well poised to fill this gap.⁶¹ One broader view includes citizens as the curators of the project, such as supporting the use and monitoring the success of living roofs and walls.⁶²

Citizen science can help guide policy in understudied habitats, such as marine and coastal habitats.⁶³ For example, citizen science has helped to assess the extent of invasive species distribution and abundance across coastal ecosystems in the eastern United States.⁶⁴ Marine policy requires large datasets at large spatial scales that are well suited to citizen science, but there has been relatively little such work in this field due to challenges with the collection of data, recruiting volunteers, and accessing sites.⁶⁵ Marine spatial planning also requires advance time and resources, making citizen science difficult.¹⁹

As with many topics in this field, the effect citizen science has on conservation outcomes and a participant's willingness to engage in further conservation action has not been investigated thoroughly.²⁰

One study found through surveys that participants developed a closer bond with study species and wanted to do more for stewardship and policy but did not follow up and check if they actually did.⁶⁶ We need more case studies to determine whether and how decision-makers use citizen science data to enact real change.²⁰

Critical challenges

Maintaining data quality and consistency

To achieve its scientific goals, data quality and consistency remains a central challenge faced by citizen science projects.⁶⁷ In one investigation, citizen science project practitioners reported that 73% of data were gathered within scientifically accepted precision parameters, although quantitative analysis of these projects suggests that a slightly lower 62% of citizen science data meet this threshold.⁶⁸ Data quality cannot be imposed by scientists, but requires good people skills in working with volunteers⁶⁹ and providing training.²⁷ With training, citizen scientists have been shown to be as good or nearly as good as experts at plant distribution and abundance (although not at identification),⁷⁰ and seabird identification.¹⁶ For identification, authors recommend complementing citizen science with reference collections.^{68,71} Recruiting specific volunteers for particular projects can enhance data quality, as researchers have found a significant interaction between education level and ability to both correctly differentiate between species and assign gender to individual animals.⁶⁴ Lastly, "team-collecting" and/or "team-entering" of data may help with data quality and consistency. Snapshot Serengeti reported 98% agreement between data entered by experts and those entered through aggregated volunteer responses, with higher concordance for common species.⁷² Given that teams of citizen scientists can be more accurate than individual volunteers,⁷⁰ 90% of images in this study were classified correctly by five volunteers per image, well below the average of 27 volunteer classifications per image.⁷²

The scientific goals of accurate data and those of education and participant satisfaction are often parallel. Citizen science projects work best when they create the proper academic, management, and data quality assurance infrastructures to ensure both successful data collection and buy-in from citizen scientists.³⁶

After data collection and entry, many modern statistical and visualization techniques can further enhance data quality. Collaboration of citizen science projects with computer scientists helps with building a data entry, data processing, data analysis, and data visualization pipeline, while collaboration with statisticians helps with developing novel analysis techniques that complete the pipeline.⁷³ Data can be checked with rapid review of records, expert screening of volunteer submissions, and accuracy-testing algorithms based on large audiences of citizen scientists contributing to a single data record.⁷⁴ Species distribution modeling and biodiversity estimates through citizen science-gathered data can be improved by adopting the use of sophisticated hierarchical models that incorporate variation in the data collection process, such as timing, sampling intensity, and observer error.^{21,71,75} For example, occupancy modeling accounts for imperfect detection in the presence of different covariates, including observer bias, and accurately monitors trends in species distributions across both space and time, but requires multiple visits to each site and careful analysis.⁷⁶

Evaluating success

In terms of the most recognized scientific currency of published papers, citizen science has contributed to many peer-reviewed articles.⁷⁷ Of papers assessing the effects of climate change on global avifauna, 24–77% of papers incorporated volunteer-gathered data with no observed decrease in trust from peer-reviewers.⁷⁸ A recent study showed that citizen science provided over half of all observations in a large-scale water quality database.⁷⁹ Assessing the numbers of publications can be difficult because the term *citizen science* only came into use in 1995,⁷⁸ and papers based on Christmas Bird Counts, for example, are typically not treated as citizen science.⁴ Longitudinal studies that track particular locations produce more scientific impact through publication in peer-reviewed journals due to the strength of citizen science in measuring trends.⁸⁰

Although long-term citizen science projects have produced a large body of scientific work,^{20,21,81} a review found that the rate of publication in peer-reviewed journals has not changed significantly in recent years.⁸² A quantitative review of 388 citizen science studies⁸³ found that only 12% of citizen science projects actively turn data into peer-reviewed

publications and that large-scale, long-term studies were most likely to get published. Major barriers to use of citizen science data include lack of awareness among scientists of citizen science projects that may fit their research needs, the consensus that many scientific investigations are not well suited for citizen science, possible inconsistency in data quality across citizen science projects, and the bias of scientists for certain types of citizen scientists.⁸² In addition, citizen science data are sometimes not used for technical reasons, such as poor formatting, organization, and analysis.⁸⁴

Many citizen science projects report their findings in more than just peer-reviewed publications.^{85,86} Wiggins *et al.* suggest that publications in scientific journals may not be the best way to measure citizen science productivity,⁸⁵ and Parrish *et al.* articulate the education, community building, and “personal fulfillment” goals of citizen science that may not always translate into scientific products like peer-reviewed publications.⁸⁶ The authors suggest using a different tool to better evaluate the productivity of citizen science—one that includes dataset creation, conservation action influence, environmental justice, and/or policy impacts. This broader view of success and productivity could facilitate a broader appreciation by reviewers and evaluators, especially when projects are being considered for funding.⁸⁵ Having a defined evaluation methodology will also help promote citizen science incorporation into and support of federal and local agencies’ work throughout a particular community.

Enhancing learning and participation

How well do participants indeed learn?⁴¹ Most citizen science projects that have evaluated the knowledge and attitude changes among their participants have noted only modest improvements in science literacy and overall attitude, but almost every project reports an increase in specific scientific knowledge and intention to engage in proenvironmental activities.^{16,63,76} However, without standardized measures, comparison across studies is difficult.⁸⁷ Involving people in the full range of the project may enhance participation and improve learning, which works best for more local problems where citizen scientists can help plan and design, as well as apply results.^{45,88}

What are the barriers that limit participation? Marginalized groups have often been

underrepresented in citizen science projects,⁴⁹ due in part to reluctance to participate in science due to a lack of comfort with the process or time constraints from work or other commitments.^{89,90} This can confine participation to only certain areas and particular residents who may not hold the same values and opinions of the local community as a whole.⁹¹ Scientists may be able to break down distrust from these communities with better public engagement, and by communicating in ways that capture the interests, backgrounds, social environments, and values of their underrepresented audiences.⁹² This communication, using social media and public events, works best when it focuses on shared values and dialog.⁹² Including participants in design of strategies for recruitment, protocols, and managing data quality¹² makes the shift from scientists using citizens to gather data to citizens themselves as scientists.²⁰

Retaining volunteers

As mentioned above, volunteer retention can be a problem for citizen science practitioners.^{15,51} To retain volunteers, scientists must understand that motivations change during the project, and this must be monitored and responded to.⁴⁰ While initial interest is key for recruitment, recognition, attribution, feedback, and community involvement are important for short-term retention, and promoting advocacy is important for long-term retention.⁹³ Attention to the differences among participants can help with retention. For citizen science “dabblers,” retention can require breaking work into small components and focusing on immediate feedback about the value of contributions.⁹⁴ Technologies like mobile apps and games open new opportunities with younger generations but can alienate those who are unfamiliar or uncomfortable, particularly older participants.⁹⁵

With online participants, Wald *et al.* found that a small number of participants complete large portions of work.⁹⁶ As virtual citizen science typically relates to entering or analyzing data gathered by someone else, breaking down barriers to participation includes using simple online interfaces, offering online help and training, interacting directly with project participants, and providing some type of social media engagement.⁹⁶ To address the low levels of retention in these online projects,¹⁷ the authors stress the importance of providing explicit,

project-based benefits to return participants. They recommend that retention involves continued communication between scientists and volunteers and sharing of data among all interested parties.⁹⁶

Contributing to community and policy

The more complex goals of building community and establishing policy have received even less attention. As evaluation of learning outcomes in citizen science programs has become increasingly prioritized among researchers, little work has been done on programmatic and community-level outcomes.⁵⁶ Suggestions for ways forward include using existing organizational and professional associations, along with open access journals and web resources, to unite the citizen science community.⁹⁵

For those seeking to influence policy, it is essential to remember that it is not just, or even primarily, science,⁹² although the two goals converge in their focus on data quality when managers do not trust citizen science data.⁶⁹ More broadly, scientists and participants can have different views of the frame of a project, with participants sometimes thinking that influencing policy is part of the goal, although scientists do not.⁹⁷

Ethical questions

When is it exploitation? Scientists benefit directly by advancing their research, but are the explicit educational, environmental, social, scientific, and community benefits for participants commensurate? Before undertaking any citizen science project, practitioners should consider carefully what explicit benefits their particular project will offer to participants and weigh these benefits against the expected time and effort that participants will be expected to give, and face the question “Are we offering enough in exchange for our citizen scientists’ aid?”

Should citizen scientists be paid? Although definitions of citizen science often assume that participation is voluntary, and therefore not something done for money, practitioners may want to consider the possibility of extending paid positions to their participants. As stated above, underrepresented and marginalized communities may be unable to participate in citizen science due to other commitments, including working commitments.^{89,90} These volunteers may be spending not only time but also money, whether through transportation, child care,

or opportunity costs, that they cannot easily afford. Extending paid positions may facilitate greater inclusivity particularly for projects with large time and effort demands. However, offering payment may not be possible, and citizen science through voluntary participation may be the only way to move a project forward. Research on the effects of paid participation, as well as cost/benefit analysis of paid participation, is needed to fully address this concern.

How should participants be acknowledged?

Although participants may be unaware of this question, sharing credit should be naturally woven into the fabric of any citizen science project. Should it be publicly as a collective, by name, or with authorship?³⁸ The form that accreditation takes must vary on a project-specific basis. For example, it is not possible for Snapshot Serengeti (<https://www.zooniverse.org/projects/zooniverse/snapshot-serengeti>), with over 11,000 individual volunteers, to offer authorship to all individual participants. But what other methods of accreditation can be offered? We do not claim to have the answer to this question, but the growing number of virtual projects and projects with online and social media presences may offer a nuanced way to accredit their participants through blogs, social media posts, or other public announcements. To our knowledge, thorough research on accreditation methods by citizen science remains a major gap, and thus a major opportunity to advance the science.

Comparison with biomedical science

Some biomedical studies parallel the ecological citizen science reviewed here, where volunteers participate in problem solving, data processing, and surveillance, with great untapped opportunity.⁹⁸ Recent reviews have classified citizen science in biomedical research, focusing on ways that citizens collect, share, and analyze data, and the ethical considerations that arise for studies that fall outside the protections developed for more traditional science.^{99,100} By contrast, we here briefly develop some parallels with the traditional medicine that continues to dominate the field, looking at the recruitment, involvement, and informing of participants.

In the majority of biomedical research, the citizen is not contributing to the study; the citizen is the

subject of study. When the participant is a patient, often critically ill, the challenges of recruiting, retaining, involving, and informing patients are fundamentally different from ecological citizen science studies. Randomized controlled trials are the gold standard of testing, where some patients are assigned a placebo or the current standard of care, while others are given a promising new treatment. Efforts to replace that with observational studies are fraught with the danger of selection bias.¹⁰¹ The principle of equipoise is that patients should be predicted to benefit from a new treatment roughly half the time, because otherwise the trial would unethically withhold a likely beneficial treatment.¹⁰²

Citizen science ecological studies are key to evaluating ecosystem health in areas best understood by local residents, but recruitment and retention of engaged volunteers is challenging. Similarly, randomized controlled trials are essential to establish health benefits to patients themselves, but they too often fail to recruit their target sample size.¹⁰³ For example, randomized controlled trials are particularly important in cancer, but less than 5% of adult cancer patients enroll in clinical trials. With 70% of patients stating they are willing, 50% with an available trial, and roughly 80% eligible, this level should instead be approximately 25%, or five times larger. The reasons for this discrepancy remain unclear, although distrust of or lack of understanding of science likely plays some role. Many fear randomization despite their hopes to improve their own outcomes and those of other patients.¹⁰⁴ As just one example of underrepresented groups, the slow improvement of cancer outcomes in adolescents and young adults relative to other age groups has been attributed in part to low participation in clinical trials, but the low participation itself remains unexplained.^{105,106}

Expansion of the role of citizens beyond simply that of patients also parallels the broader roles of citizen scientists in ecology beyond data collection or entry assistants. Current trials, like much of current medicine, seek to involve patients in every step, from choosing questions, designing and conducting the research, and implementing results, in what is called patient-centered outcomes research.¹⁰⁷ As with much of citizen science in ecology, the effects have not been well studied. There is some evidence that chosen questions are more consonant with patient needs, executed better in

terms of recruitment and retention, and translated in terms of dissemination and use. Drawbacks are the time and money required, and the potential to turn these steps into just another a checkbox rather than real engagement.¹⁰⁷ The “patient and public involvement” movement involves patients in trial design and delivery, but there is still little assessment or even definition of this approach.¹⁰³

The most effective citizen science projects in ecology and the environment share results broadly and clearly. This challenge is accentuated in the highly personal realm of clinical trials. How and when should patients be informed of trial outcomes? Who develops and pays for the information-sharing plan?¹⁰⁸ Given the principle of equipoise, half of the patients are likely to have done poorly based on the arm to which they were assigned. How do patients look back on their decision to join a trial after learning that many patients, themselves possibly included, did poorly? In one study, most accepted with the fact that some arms increased adverse outcomes, but some felt guilt, betrayal, and a loss of trust. However, most of the participants in this study were happy to receive the results and came to terms with the fact that they did not benefit and that the trial in fact did not work.¹⁰⁹ In a large trial of antibiotic use in pregnancy, less than 20% said they wanted a summary, and those who did often wanted to see which arm they were in and were disappointed to get a general summary in the form of a leaflet.¹¹⁰

In the media, stories about health often receive the most coverage. For example, the top four feature stories in *Science News* in 2019 covered Vitamin D supplements, the effects of measles on the immune system, long-term effects of shingles, and the lack of sufficient study of cannabidiol.¹¹¹ Each of these requires long-term study of human subjects. The often-heard criticism of inconsistency, such as in recommendations about healthy diets and lifestyles, may result from the challenges of recruiting sufficiently large and representative groups and from communicating the results to both participants and the broader public. These challenges recall those of involving citizens in understanding and restoring the health of ecosystems.

Conclusions

Working with people can be a messy business, and science has traditionally been set up to avoid that.

Some scientists even pride themselves on being antisocial (F.R. Adler, personal observation). But science is done by people, and for purposes that matter to people, whether for the curiosity we share, for education, or to promote health, community, or policy. People can be challenging to motivate, train, retain, and respect. Citizen science, by explicitly including nonscientists, must address all of these motives and all of these challenges. We do not argue that the ideal of scientific objectivity is obsolete and should be ignored, but instead that we must all think carefully about how that ideal interacts with the reality of human motivation and goals. Citizen science provides a window into the challenge of science in the real world, and we thus conclude with some lessons learned about the practice of science in this new era.

Science as a whole has entered an era of team science and interdisciplinary science, which has become a field of study in its own right.¹¹² Citizen science is necessarily interdisciplinary, and eBird provides a strong example, with collaborations of biologists, computer scientists, statisticians, GIS specialists, and data scientists to recruit and engage volunteers, produce large quantities of expert-validated data, and answer multiple independent research questions.¹¹³ More broadly, we have the opportunity to coordinate among projects¹¹⁴ despite the challenge of transferring success between projects with different goals,⁵⁵ and of creating good protocols, data collection methods, and questions.¹¹⁵ The difficulty of coordinating goals and methods in team science is accentuated in citizen science with the larger challenges of involving participants more deeply in the whole process.¹⁴ Such codesigned projects are few and far between and represent a major avenue for advancement of citizen science.⁶⁷

Of course, there remains much to investigate about citizen science.^{67,116} Sociologists could help investigate motivations, behavioral and attitudinal changes, and retention of participants.^{73,114} Knowledge gaps include understanding factors that promote success of citizen scientists both positively influencing environmental change and their own environmental knowledge, and case studies of decision-makers using citizen science data to enact real change.²⁰

There are many good frameworks for citizen science¹¹⁷ and many good models to follow or join.

The European Citizen Science Association has laid out 10 principles for actively and ethically involving citizens in real science that is useful for all parties.⁶⁷ This broad view, perhaps reaching out to include biomedical science, will allow us to coproduce science policy in ways that defeat the “tyranny of small decisions” and lead to more legitimate environmental policies and decisions.¹¹⁸ Including the human element in science can thus not only help science itself, but also promote science that more effectively helps humanity.

Acknowledgments

Support was provided to F.R.A. by the Modeling Dynamics of Life Fund at the University of Utah. We thank Adam Cohen for providing references to the biomedical literature.

Competing interests

The authors declare no competing interests.

References

- Ryan, A.G. & G.S. Aikenhead. 1992. Students' preconceptions about the epistemology of science. *Sci. Educ.* **76**: 559–580.
- Brush, S.G. 1974. Should the history of science be rated X?: the way scientists behave (according to historians) might not be a good model for students. *Science* **183**: 1164–1172.
- McComas, W.F. 1998. The principal elements of the nature of science: dispelling the myths. In *The Nature of Science in Science Education*. W.F. McComas, Ed.: 53–70. Los Angeles, CA: Springer.
- Haklay, M. 2013. Citizen science and volunteered geographic information: overview and typology of participation. In *Crowdsourcing Geographic Knowledge*. D. Sui, S. Elwood & M. Goodchild, Eds.: 105–122. Springer.
- Simonton, D.K. 2013. After Einstein: scientific genius is extinct. *Nature* **493**: 602.
- Khan, I. 2015. Science: not just for scientists. *The Guardian*. December 1.
- Golubiewski, N. 2012. Is there a metabolism of an urban ecosystem? An ecological critique. *Ambio* **41**: 751–764.
- Rapport, D. 1998. Defining ecosystem health. In *Ecosystem Health: Principles and Practice*. D.J. Rapport, C.L. Gaudet, R. Constanza, P.R. Epstein & R. Levins, Eds.: 18–33. John Wiley and Sons.
- Adler, F.R. & C.J. Tanner. 2013. *Urban Ecosystems: Ecological Principles for the Built Environment*. New York: Cambridge University Press.
- Skloot, R. 2010. *The Immortal Life of Henrietta Lacks*. New York: Crown Publishers.
- Silverton, J. 2009. A new dawn for citizen science. *Trends Ecol. Evol.* **24**: 467–471.
- Bonney, R., T.B. Phillips, H.L. Ballard & J.W. Enck. 2016. Can citizen science enhance public understanding of science? *Public Underst. Sci.* **25**: 2–16.
- Wiggins, A. & K. Crowston. 2011. *From Conservation to Crowdsourcing: A Typology for Citizen Science*. Kauai, HI: IEEE.
- Shirk, J.L., H.L. Ballard, C.C. Wilderman, *et al.* 2012. Public participation in scientific research: a framework for deliberate design. *Ecol. Soc.* **17**: 29.
- Sauermann, H. & C. Franzoni. 2015. Crowd science user contribution patterns and their implications. *Proc. Natl. Acad. Sci. USA* **112**: 679–684.
- Haywood, B.K., J.K. Parrish & J. Dolliver. 2016. Place-based and data-rich citizen science as a precursor for conservation action. *Conserv. Biol.* **30**: 476–486.
- Parrish, J.K., T. Jones, H.K. Burgess, *et al.* 2019. Hoping for optimality or designing for inclusion: persistence, learning, and the social network of citizen science. *Proc. Natl. Acad. Sci. USA* **116**: 1894–1901.
- Devictor, V., R.J. Whittaker & C. Beltrame. 2010. Beyond scarcity: citizen science programmes as useful tools for conservation biology. *Divers. Distrib.* **16**: 354–362.
- Jarvis, R.M., B.B. Breen, C.U. Krageloh & D.R. Billington. 2015. Citizen science and the power of public participation in marine spatial planning. *Mar. Policy* **57**: 21–26.
- Conrad, C.C. & K.G. Hilchey. 2011. A review of citizen science and community-based environmental monitoring: issues and opportunities. *Environ. Monit. Assess.* **176**: 273–291.
- Horns, J.J., F.R. Adler & C.H. Şekercioglu. 2018. Using opportunistic citizen science data to estimate avian population trends. *Biol. Conserv.* **221**: 151–159.
- Abolafya, M., O. Onmuş, Ç.H. Şekercioglu & R. Bilgin. 2013. Using citizen science data to model the distributions of common songbirds of Turkey under different global climatic change scenarios. *PLoS One* **8**: e68037.
- Neate-Clegg, M.H., S.E. Jones, O. Burdekin, *et al.* 2018. Elevational changes in the avian community of a mesoamerican cloud forest park. *Biotropica* **50**: 805–815.
- Chandler, M., L. See, K. Copas, *et al.* 2017. Contribution of citizen science towards international biodiversity monitoring. *Biol. Conserv.* **213**: 280–294.
- Gallo, T. & D. Watt. 2011. Creating a successful citizen science model to detect and report invasive species. *BioScience* **61**: 459–465.
- Hawthorne, T.L., V. Elmore, A. Strong, *et al.* 2015. Mapping non-native invasive species and accessibility in an urban forest: a case study of participatory mapping and citizen science in Atlanta, Georgia. *Appl. Geogr.* **56**: 187–198.
- Dickinson, J.L., B. Zuckerberg & D.N. Bonter. 2010. Citizen science as an ecological research tool: challenges and benefits. *Annu. Rev. Ecol. Evol. Syst.* **41**: 49–72.
- Meentemeyer, R.K., M.A. Dorning, J.B. Vogler, *et al.* 2015. Citizen science helps predict risk of emerging infectious diseases. *Front. Ecol. Environ.* **13**: 189–194.
- Curtis-Robles, R., E.J. Wozniak, L.D. Auckland, *et al.* 2015. Combining public health education and disease ecology research: using citizen science to assess Chagas disease entomological risk in Texas. *PLoS Negl. Trop. Dis.* **12**: e0004235.

30. Miller-Rushing, A., R. Primack & R. Bonney. 2012. The history of public participation in ecological research. *Front. Ecol. Environ.* **10**: 285–290.
31. Lepczyk, C.A. 2005. Integrating published data and citizen science to describe bird diversity across a landscape. *J. Appl. Ecol.* **42**: 672–677.
32. Chandler, M., D.P. Bebbler, S. Castro, *et al.* 2012. International citizen science: making the local global. *Front. Ecol. Environ.* **10**: 328–331.
33. Horton, K.G., B.M. Van Doren, F.A. La Sorte, *et al.* 2019. Holding steady: little change in intensity or timing of bird migration over the Gulf of Mexico. *Glob. Chang. Biol.* **25**: 1106–1118.
34. Hurlbert, A.H. & Z. Liang. 2012. Spatiotemporal variation in avian migration phenology: citizen science reveals effects of climate change. *PLoS One* **7**: e31662.
35. Sullivan, B.L., T. Phillips, A.A. Dayer, *et al.* 2017. Using open access observational data for conservation action: a case study for birds. *Biol. Conserv.* **208**: 5–14.
36. Cooper, C., J. Dickinson, T. Phillips & R. Bonney. 2007. Citizen science as a tool for conservation in residential ecosystems. *Ecol. Soc.* **12**: 11.
37. McCaffrey, E.R. 2005. Using citizen science in urban bird studies. *Urban Habitats* **3**: 70–86.
38. Dickinson, J.L., J. Shirk, D. Boner, *et al.* 2012. The current state of citizen science as a tool for ecological research and public engagement. *Front. Ecol. Environ.* **10**: 291–297.
39. Lee, T., M.S. Quinn & D. Duke. 2006. Citizen, science, highways, and wildlife: using a web-based GIS to engage citizens in collecting wildlife information. *Ecol. Soc.* **11**: 11.
40. Rotman, D., J. Preece, J. Hammock, *et al.* 2012. Dynamic changes in motivation in collaborative citizen-science projects. In *Proceedings of the ACM 2012 Conference on Computer Supported Cooperative Work - CSCW '12*, ACM Press.
41. Bela, G., T. Peltola, J.C. Young, *et al.* 2016. Learning and the transformative potential of citizen science. *Conserv. Biol.* **30**: 990–999.
42. Groulx, M., M.C. Brisbois, C.J. Lemieux, *et al.* 2017. A role for nature-based citizen science in promoting individual and collective climate change action? A systematic review of learning outcomes. *Sci. Commun.* **39**: 45–76.
43. Land-Zandstra, A.M., J.L.A. Devilee, F. Snik, *et al.* 2016. Citizen science on a smartphone: participants' motivations and learning. *Public Underst. Sci.* **25**: 45–60.
44. Masters, K., E.Y. Oh, J. Cox, *et al.* 2016. Science learning via participation in online citizen science. *Sci. Commun.* **15**: 1–33.
45. Jordan, R.C., S.A. Gray, D.V. Howe, *et al.* 2011. Knowledge gain and behavioral change in citizen-science programs. *Conserv. Biol.* **25**: 1148–1154.
46. Curtis, V. 2015. Motivation to participate in an online citizen science game: a study of Foldit. *Sci. Commun.* **37**: 723–746.
47. Eiben, C.B., J.B. Siegel, J.B. Bale, *et al.* 2012. Increased Diels–Alderase activity through backbone remodeling guided by Foldit players. *Nat. Biotechnol.* **30**: 190.
48. Khatib, F., F. DiMaio, S. Cooper, *et al.* 2011. Crystal structure of a monomeric retroviral protease solved by protein folding game players. *Nat. Struct. Mol. Biol.* **18**: 1175.
49. Trumbull, D.J., R. Bonney, D. Bascom & A. Cabral. 2000. Thinking scientifically during participation in a citizen-science project. *Sci. Educ.* **84**: 265–275.
50. Evans, C., E. Abrams, R. Reitsma, *et al.* 2005. The Neighborhood Nestwatch Program: participant outcomes of a citizen-science ecological research project. *Conserv. Biol.* **19**: 589–594.
51. Seymour, V. & M. Haklay. 2017. Exploring engagement characteristics and behaviours of environmental volunteers. *Citiz. Sci. Theory Pract.* **2**: 5.
52. Aristeidou, M., E. Scanlon & M. Sharples. 2017. Profiles of engagement in online communities of citizen science participation. *Comput. Hum. Behav.* **74**: 246–256.
53. Alexandrino, E.R., A.B. Navarro, V.F. Paulete, *et al.* 2019. Challenges in engaging birdwatchers in bird monitoring in a forest patch: lessons for future citizen science projects in agricultural landscapes. *Citiz. Sci. Theory Pract.* **4**: 4.
54. Nov, O., O. Arazy & D. Anderson. 2014. Scientists@home: what drives the quantity and quality of online citizen science participation. *PLoS One* **9**: e90375.
55. Freitag, A. & M.J. Pfeffer. 2013. Process, not product: investigating recommendation for improving citizen science 'success'. *PLoS One* **8**: e64079.
56. Jordan, R.C., H.L. Ballard & T.B. Phillips. 2012. Key issues and new approaches for evaluating citizen-science learning outcomes. *Front. Ecol. Environ.* **10**: 307–309.
57. Marshall, N.J., D.A. Kleine & A.J. Dean. 2012. Coralwatch: education, monitoring, and sustainability through citizen science. *Front. Ecol. Environ.* **10**: 332–334.
58. Cox, J., E.Y. Oh, B. Simmons, *et al.* 2015. How is success defined and measured in online citizen science? A case study of Zooniverse projects. *Comput. Sci. Eng.* **17**: 28–41.
59. Eden, S. 1996. Public participation in environmental policy: considering scientific, counter-scientific and non-scientific contributions. *Public Underst. Sci.* **5**: 183–204.
60. Mckinley, D.C., A.J. Miller-Rushing, H.L. Ballard, *et al.* 2017. Citizen science can improve conservation science, natural resource management, and environmental protection. *Biol. Conserv.* **208**: 15–28.
61. Couvet, D., F. Jiguet, R. Julliard, *et al.* 2008. Enhancing citizen contributions to biodiversity science and public policy. *Interdiscip. Sci. Rev.* **33**: 95–103.
62. Francis, R.A. & J. Lorimer. 2011. Urban reconciliation ecology: the potential of living roofs and walls. *J. Environ. Manage.* **92**: 1429–1437.
63. Cigliano, J.A., R. Meyer, H.L. Ballard, *et al.* 2015. Making marine and coastal citizen science matter. *Ocean Coast. Manag.* **115**: 77–87.
64. Delaney, D.G., C.D. Sperling, C.S. Adams & B. Leung. 2007. Marine invasive species: validation of citizen science and implications for national monitoring networks. *Biol. Invasions* **10**: 117–128.

65. Hyder, K., B. Townhill, L.G. Anderson, *et al.* 2015. Can citizen science contribute to the evidence-base that underpins marine policy? *Mar. Policy* **59**: 112–120.
66. Toomey, A.H. & M.C. Domroese. 2013. Can citizen science lead to positive conservation attitudes and behaviors? *Hum. Ecol. Rev.* **20**: 50–62.
67. Hecker, S., R. Bonney, M. Haklay, *et al.* 2018. Innovation in citizen science—perspectives on science-policy advances. *Citiz. Sci. Theory Pract.* **3**: 1–14.
68. Aceves-Bueno, E., A.S. Adeleye, M. Feraud, *et al.* 2017. The accuracy of citizen science data: a quantitative review. *Bull. Ecol. Soc. Am.* **98**: 278–290.
69. Vann-Sander, S., J. Clifton & E. Harvey. 2016. Can citizen science work? Perceptions of the role and utility of citizen science in a marine policy and management context. *Mar. Policy* **72**: 82–93.
70. Crall, A.W., G.J. Newman, T.J. Stohlgren, *et al.* 2011. Assessing citizen science data quality: an invasive species case study. *Conserv. Lett.* **4**: 433–442.
71. Bird, T.J., A.E. Bates, J.S. Lefcheck, *et al.* 2014. Statistical solutions for error and bias in global citizen science dataset. *Biol. Conserv.* **173**: 144–154.
72. Swanson, A., M. Kosmala, C. Lintott & C. Packer. 2015. A generalized approach for producing, quantifying, and validating citizen science data from wildlife images. *Conserv. Biol.* **30**: 520–531.
73. Hochachka, W.M., D. Fink, R.A. Hutchinson, *et al.* 2012. Data-intensive science applied to broad-scale citizen science. *Trends Ecol. Evol.* **27**: 130–137.
74. Bonter, D.N. & C.B. Cooper. 2012. Data validation in citizen science: a case study from Project FeederWatch. *Front. Ecol. Evol.* **10**: 305–307.
75. Isaac, N.J.B., A.J. van Strien, T.A. August, *et al.* 2014. Statistics for citizen science: extracting signals of change from noisy ecological data. *Methods Ecol. Evol.* **5**: 1052–1060.
76. van Strien, J.A., C.A.M. van Swaay & T. Termaat. 2015. Opportunistic citizen science data of animal species produce reliable estimates of distribution trends if analysed with occupancy models. *J. Appl. Ecol.* **50**: 1450–1458.
77. Bonney, R., J.L. Shirk, T.B. Phillips, *et al.* 2014. Next steps for citizen science. *Science* **343**: 1436–1437.
78. Cooper, C.B., J. Shirk & B. Zuckerberg. 2014. The invisible prevalence of citizen science in global research: migratory birds and climate change. *PLoS One* **9**: e106508.
79. Poisson, A.C., I.M. McCullough, K.S. Cheruvilil, *et al.* 2020. Quantifying the contribution of citizen science to broad-scale ecological databases. *Front. Ecol. Environ.* **18**: 19–26.
80. Tullock, A.I.T., H.P. Possingham, L.N. Joseph, *et al.* 2013. Realising the full potential of citizen science monitoring programs. *Biol. Conserv.* **165**: 128–138.
81. Callaghan, C.T. & D.E. Gawlik. 2015. Efficacy of eBird data as an aid in conservation planning and monitoring. *J. Field Ornithol.* **86**: 298–304.
82. Burgess, H.K., L.B. DeBey, H.E. Froehlich, *et al.* 2017. The science of citizen science: exploring barriers to use as a primary research tool. *Biol. Conserv.* **208**: 113–120.
83. Theobald, E.J., A.K. Ettinger, H.K. Burgess, *et al.* 2015. Global change and local solutions: tapping the unrealized potential of citizen science for biodiversity research. *Biol. Conserv.* **181**: 236–244.
84. Kim, S., C. Robson, T. Zimmerman, *et al.* 2011. Creek Watch: pairing usefulness and usability for successful citizen science. *CHI Paper*. ACM Press.
85. Wiggins, A., R. Bonney, G. LeBuhn, *et al.* 2018. A science products inventory for citizen-science planning and evaluation. *BioScience* **68**: 436–444.
86. Parrish, J.K., H. Burgess, J.F. Weltzin, *et al.* 2018. Exposing the science in citizen science: fitness to purpose and intentional design. *Integr. Comp. Biol.* **58**: 150–160.
87. Crall, A.W., R. Jordan, K. Holfelder, *et al.* 2012. The impacts of an invasive species citizen science training program on participant attitudes, behavior, and science literacy. *Public Underst. Sci.* **22**: 745–764.
88. Ramirez-Andreotta, M.D., M.L. Brusseau, J. Artiola, *et al.* 2015. Building a co-created citizen science program with gardeners neighboring a superfund site: the Gardenroots case study. *Int. Public Health J.* **7**: 139.
89. Levine, R., R. González & C. Martínez-Sussmann. 2009. Learning diversity in earth system science. Committee for the Review of the NOAA Education Program, National Research.
90. Jolly, E.J. 2002. Confronting demographic denial: retaining relevance in the new millennium. *J. Mus. Educ.* **27**: 3–6.
91. Pandya, R.E. 2012. A framework for engaging diverse communities in citizen science in the US. *Front. Ecol. Environ.* **10**: 314–317.
92. Groffman, P.M., C. Stylinski, M.C. Nisbet, *et al.* 2010. Restarting the conversation: challenges at the interface between ecology and society. *Front. Ecol. Environ.* **8**: 284–291.
93. Rotman, D., J. Hammock, J. Preece, *et al.* 2014. Motivation affecting initial and long-term participation in citizen science projects in three countries. In *iConference 2014 Proceedings*, 110–124.
94. Eveleigh, A., C. Jennett, A. Blandford, *et al.* 2014. Designing for dabblers and deterring drop-outs in citizen science. In *Proceedings of the 32nd Annual ACM Conference on Human Factors in Computing Systems—CHI*, ACM Press.
95. Newman, G., A. Wiggins, A. Crall, *et al.* 2012. The future of citizen science: emerging technologies and shifting paradigms. *Front. Ecol. Environ.* **10**: 298–304.
96. Wald, D.M., J. Longo & A. Dobell. 2016. Design principles for engaging and retaining virtual citizen scientists. *Conserv. Biol.* **30**: 562–570.
97. Toogood, M. 2013. Engaging publics: biodiversity data collection and the geographies of citizen science. *Geogr. Compass* **7**: 611–621.
98. Ranard, L.B., Y.B. Ha, Z.F. Meisel, *et al.* 2013. Crowdsourcing – harnessing the masses to advance health and medicine, a systematic review. *J. Gen. Intern. Med.* **29**: 187–203.
99. Wiggins, A. & J. Wilbanks. 2019. The rise of citizen science in health and biomedical research. *Am. J. Bioeth.* **19**: 3–14.

100. Fiske, A., L. Del Savio, B. Prainsack & A. Buyx. 2018. Conceptual and ethical considerations for citizen science in biomedicine. In *Personal Health Science*. N.B. Heyen, S. Dickel & A. Brüninghaus, Eds.: 195–217. Springer.
101. Collins, R., L. Bowman, M. Landray & R. Peto. 2020. The magic of randomization versus the myth of real-world evidence. *N. Engl. J. Med.* **382**: 674–678.
102. Freedman, B. 1987. Equipoise and the ethics of clinical research. *N. Engl. J. Med.* **317**: 141–145.
103. Planner, C., A. Bower, K. Gillies, *et al.* 2019. Trials need participants but not their feedback? A scoping review of published papers on the measurement of participant experience of taking part in clinical trials. *Trials* **20**: 381.
104. Unger, J.M., E. Cook, E. Tai & A. Bleyer. 2016. The role of clinical trial participation in cancer research: barriers, evidence, and strategies. *Am. Soc. Clin. Oncol. Educ. Book* **36**: 185–198.
105. Roth, M.E., A.M. O'Mara, N.L. Seibel, *et al.* 2016. Low enrollment of adolescents and young adults onto cancer trials: insights from the community clinical oncology program. *J. Oncol. Pract.* **12**: e388–e395.
106. Bleyer, A., E. Tai & S. Siegel. 2018. Role of clinical trials in survival progress of American adolescents and young adults with cancer— and lack thereof. *Pediatr. Blood Cancer* **65**: e27074.
107. Garcés, J.P.D., G.J.P. Lopez, Z. Wang, *et al.* 2012. *Eliciting patient perspective in patient-centered outcomes research: a meta narrative systematic review. A report prepared for the Patient-Centered Outcomes Research Institute*. Mayo Clinic, Rochester, MN.
108. Ferris, L.E. & A. Sass-Kortsak. 2011. Sharing research findings with research participants and communities. *Int. J. Occup. Environ. Med.* **2**: 172–181 .
109. Tarrant, C., C. Jackson, M. Dixon-Woods, *et al.* 2015. Consent revisited: the impact of return of results on participants' views and expectations about trial participation. *Health Expect.* **18**: 2042–2053.
110. Dixon-Woods, M., C. Jackson, K.C. Windridge & S. Kenyon. 2006. Receiving a summary of the results of a trial: qualitative study of participants' views. *Br. Med. J.* **332**: 206–210.
111. Staff Science News. 2019. Top 10 stories of 2019. *Science News, Vol. 196*, December 21.
112. Stokols, D., K.L. Hall, B.K. Taylor & R.P. Moser. 2008. The science of team science: overview of the field and introduction to the supplement. *Am. J. Prev. Med.* **35**: S77–S89.
113. Sullivan, B.L., J.L. Aycrigg, J.H. Barry, *et al.* 2014. The eBird enterprise: an integrated approach to development and application of citizen science. *Biol. Conserv.* **169**: 31–40.
114. Kobori, H., J.L. Dickinson, I. Washitani, *et al.* 2015. Citizen science: a new approach to advance ecology, education, and conservation. *Ecol. Res.* **31**: 1–19.
115. Loss, S.R., S.S. Loss, T. Will & P.P. Marra. 2015. Linking place-based citizen science with large-scale conservation research: a case study of bird–building collisions and the role of professional scientists. *Biol. Conserv.* **184**: 439–445.
116. Jordan, R., A. Crall, S. Gray, *et al.* 2015. Citizen science as a distinct field of inquiry. *BioScience* **65**: 208–211.
117. Bonney, R., C.B. Cooper, J. Dickinson, *et al.* 2009. Citizen science: a developing tool for expanding science knowledge and scientific literacy. *BioScience* **59**: 977–984.
118. Coburn, J. 2007. Community knowledge in environmental health science: co-producing policy expertise. *Environ. Sci. Policy* **10**: 150–161.