



## Review article

# Narrative review of citizen science in environmental epidemiology: Setting the stage for co-created research projects in environmental epidemiology

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## ABSTRACT

Several citizen science (CS) initiatives have been adopted in environmental science to monitor air and noise pollution, and water quality related to civic concerns. Nevertheless, CS projects in environmental epidemiology remain scarce. This is because little attention has been paid to evaluate associations of environmental exposures with health effects directly. This narrative review aims to promote the understanding and application of CS in environmental epidemiology. There are many commonalities between CS and other participatory approaches in environmental epidemiology. Yet, CS can foster the democratization of scientific governance and enhance the sustainability of research projects more effectively than other existing participatory approaches. This is especially the case in projects where citizens are invited to participate, engage and become involved throughout all the phases of a research project (co-created projects). This paper identifies various challenges and opportunities specific to the implementation of co-created CS projects in environmental epidemiology. The development of more locally relevant research designs, using local knowledge, obtaining medical ethical clearance, and co-analysing the association between exposure and health, are examples of opportunities and challenges that require epidemiologists to go beyond the traditional research framework and include more outreach activities. Continued efforts, particularly the sharing of information about projects' collaborative processes, are needed to make CS a more concrete and cohesive approach in environmental epidemiology.

## 1. Introduction

Citizens (or non-professional researchers) have been doing research in the form of "citizen science" (CS) for centuries in some cases predating

institutionalised research (Sauermann et al., 2020). Though citizens having an active role in science is not a new phenomenon, narrowing the gap between science and society remains a challenge that needs to be addressed. The current lack of public trust in science has led scientists

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and scientific institutions to adopt more extensive participatory models (Saltelli & Funtowicz, 2017). A seminal contribution to this debate is in Funtowicz and Ravetz (1993), who laid the foundation for what has become known as post-normal science. In Europe, several stakeholders in science, research and innovation have started to rethink ways of reconnecting science with society and other modes of public participation in science, such as CS. Though practices qualified as CS are flourishing, they are not supported by a common definition, resulting in various interpretations and implementation strategies of CS worldwide (Eitzel et al., 2017). Multiple authors have articulated diverse taxonomies and criteria to help develop a shared understanding of CS (Heigl et al., 2019). The inherent premise in all of the published definitions of CS is that it should provide citizens with the opportunity to be involved in the research process (Buyx et al., 2017). Of note, the term “citizen” does not reflect the citizenship status of people contributing to a project but is used to distinguish the lay public from professional researchers.

CS is an approach that has gained recognition within various scientific and civic communities, such as environmental sciences, which includes biology, biodiversity conservation and ecology research. These fields mainly utilise CS to collect large amounts of observations and classify data, an approach inspiring other fields such as medicine and psychology (Kullenberg and Kasperowski, 2016, Pykett et al., 2020). In the field of environmental health, the current re-found enthusiasm for CS is largely attributed to the proliferation and integration of information and communication technology into everyday life through the internet, computers, smartphones, social media and low-cost open-source sensing technologies (Woolley et al., 2016, Barrett et al., 2013). CS has been used to monitor air and noise pollution, water quality and odour nuisance to address concerns from citizens and strengthen public health policies (EEA, 2019, Berti Suman and van Geenhuizen, 2020, Quinlivan et al., 2020, Capelli et al., 2019, Zipf et al., 2020). Examples of these projects include the CurieuzeNeuzen project in Belgium (Van Brussel and Huyse, 2019), the SamenMeten platform in the Netherlands (Wesseling et al., 2019), and the Plaça del Sol mapping noise project in Barcelona (Woods et al., 2018).

Environmental studies have started utilising CS more frequently to address issues identified by communities that are disproportionately affected by environmental hazards related to poor air quality, industrial water and soil contamination, to mention a few (Averett, 2017; Temper et al., 2015). However, these CS initiatives do not explicitly study the health effects related to measured exposures.

Characterization of health effects related to the established exposure of a population can be done using a health impact assessment. In this setting, the possible health effect is then calculated based upon existing exposure–response relationships from scientific literature (Nieuwenhuijsen et al., 2017, Barzyk et al., 2018). When no existing exposure–response relationships exist, using a local epidemiological study setting may be more appropriate. This setting involves the collection of local data on exposure, health and other risk factors, from which the relationships between exposure and health can be analyzed (Nieuwenhuijsen, 2015). Savitz (2016) has provided comments on the usefulness of local epidemiological studies depending on factors such as the size of the exposed population. CS is still a new participatory approach within environmental epidemiology that needs more attention. That is why this narrative review will only focus on the application of CS in environmental epidemiology.

Within environmental epidemiology, experts have expressed a keen interest in working with the communities by making their research more socially responsible, ethical, open, inclusive and sustainable (Kramer et al., 2012, Weed & McKeown, 2003, O’Fallon & Dearry, 2002). Despite these developments, bottom-up CS projects in environmental epidemiology are rare. CS has not only caught the attention of experts, but also that of citizens who want to actively contribute to issues of concern to them (Martin et al., 2016, Van Brussel and Huyse, 2019). A well-known example of this public interest towards CS is the “CurieuzeNeuzen” project. This is a bottom-up air quality measuring initiative created by

the Ringland Academy, a think tank composed of volunteer experts and committed citizens based in Antwerp, Belgium. Only a few days after announcing the start of the project, 2600 citizens registered to participate.

This paper was prepared using the Citizen Science on Urban Environment and Health framework (CiteS-Health, 2020). CiteS-Health is an EU Horizon 2020 programme funded project on CS in environmental epidemiology. This narrative review aims to promote the understanding and application of CS in environmental epidemiology. While prior work has introduced the concept of CS in environmental and public health, this is the first attempt to describe the application of CS in this field (English et al., 2018; Den Broeder et al., 2018). This paper provides readers with a background on the definition of CS and popular CS taxonomies. CS is not the only participatory approach used in environmental epidemiological studies, thus this paper will also describe participatory trends in environmental epidemiological research on which CS projects can fruitfully build. This is followed by the proposal of a general framework that environmental epidemiologists can use to implement CS throughout the research process. The next section focuses on the rationales for CS and how this approach is beneficial for both citizens and researchers. Finally, the last section highlights some of the challenges researchers may face when implementing CS in environmental epidemiology.

## 2. Citizen science: definitions and trends in environmental epidemiology

### 2.1. Definitions of citizen science

CS encompasses a variety of activities and approaches that connects the public with scientific research. As early as 1969, researchers have started to describe the degrees of civic participation in research for example Arnstein’s ladder of citizen participation (Arnstein, 1969). Currently, the oldest, documented, ongoing CS project is the Audubon Society’s Christmas Bird Count which started in 1900 (Miller-Rushing et al., 2012). Independently coined by Alan Irwin in 1995 and Rick Bonney in 1996, CS has two distinct definitions. The main difference between Irwin and Bonney’s definitions is the degree of public engagement and ownership of knowledge (Irwin, 1995, Bonney, 1996). Bonney’s definition paved the way for the “productivity view” of CS, where the main rationale for scientists to include citizens is to accelerate the generation of scientific knowledge by mobilizing the additional ‘low cost resources’ generated by citizens (Sauermaun et al., 2020, Christian et al., 2012, Khatib et al., 2011, Nielsen, 2011). In this case, any knowledge is seen as a valuable outcome that will eventually benefit society in some way. Studies oriented towards this view remain “top-down” initiatives, where experts have the role of improving public scientific literacy and public trust in science (Woolley et al., 2016). The productivity view shares similar objectives to large traditional environmental epidemiology studies, that is, the need to collect large amounts of data. Instead, Irwin’s notion is that the value of knowledge depends on the needs and preferences of society (Irwin, 1995) giving rise to the “democratisation view” of CS (Sauermaun et al., 2020). Studies following this view favour citizens’ control over decisions and ownership of the project over the institutional and academic standards.

Most of the CS projects currently available to citizens are only contributory in nature, meaning that the projects are often initiated and led by professional scientists working in an academic setting (Sauermaun et al., 2020, Franzoni and Sauermaun, 2014, Hecker et al., 2018, Bio Service Innovation, 2018, Science Europe, 2018). Though current literature reflects researchers’ interest in the productive power of CS, we argue that the true added benefit of CS in environmental epidemiology lies in its ability to democratise epidemiological research. Although the productivity view has its own benefits, it does not sufficiently address concerns about the content of research, especially projects aiming to investigate local problems, or provide findings tailored to support

citizens' needs for change in their immediate environment (discussed in Section 3.1).

The emergence of CS has strong links with the discussions regarding the changing role of scientists in policy relevant research. In the early 1990s Funtowicz and Ravetz developed an approach called post-normal science to deal with issues where “facts are uncertain, values in dispute, stakes high and decisions urgent” (1993, p.744). In such cases, quality assurance can no longer be restricted to researchers and experts of particular disciplines but must involve an ‘extended peer community’ with the participation of all the stakeholders in the issue (Funtowicz and Ravetz, 1993).

Terminology rarely remains static, consequently the rapidly growing and diversifying groups of participants and disciplines involved in CS has allowed the term CS to become particularly dynamic (Eitzel et al., 2017). This led to the development of various CS taxonomies on how CS should be done such as contractual, contributory, collaborative, co-created, collegial and autonomous CS (Welvaert & Caley, 2016, Sauermann et al., 2020, Follett and Strezov, 2015, Bonney et al., 2009, Hecker et al., 2018, Shirk et al., 2012). Contributory CS refers to the limited participation of citizens in research, often related to data collection or data processing, whereas collaborative CS invites citizens to take part in more research activities. Both contributory and collaborative CS do not necessarily aim to build a reciprocal relationship between citizens and scientists where they share power and decision-making responsibilities. Co-created CS implies the full involvement of the citizens in the conduct and governance of the research project with the scientists. The co-created CS methodology could provide environmental epidemiology the opportunity to create dynamic feedback systems between researchers and citizens, ensuring that the focus of the project is more in line with the interest of society (Eleta et al., 2019). Moreover, CS does not always require the input of experts and research institutions in a project. Citizens can and have started creating their own research projects without necessarily being recruited by scientists, known as collegial, autonomous or extreme CS (Shirk et al., 2012, Haklay, 2013, Balestrini et al., 2017, Buyx et al., 2017, Constant, 2018, Sauermann et al., 2020). Due to the variation and subtleties of the disciplinary context of each project, the need for a universal taxonomy of CS addressed by various authors, practitioners and funders has rapidly dissipated (Heigl et al., 2019, Ceccaroni et al., 2017). The attempts to define a single universal definition for CS have seemed to be more problematic than helpful (Haklay et al., 2020). Other authors have argued that a single definition prevents creativity and evolution of CS within the field (Auerbach et al., 2019) and uproots CS terminologies from their geopolitical settings (Eitzel et al., 2017).

Recognising the flexibility of the concept of CS, the European Citizen Science Association (ECSA) summarised the best practice of CS in ten principles that can be adapted to specific situations (Robinson et al., 2018). In short, the ten principles suggest that CS projects are projects where a meaningful role is given to citizens to generate new knowledge, where both experts and citizens benefit from the research and where open data-sharing is recommended. Recently ECSA has set out to define the characteristics of CS to address ambiguities surrounding the meaning of CS in specific fields of research. These characteristics were not defined to restrict CS, but to provide more grounding on what should and should not be considered as CS to funders and practitioners in Europe (Haklay et al., 2020). The three most relevant characteristics of interest and relevance to environmental epidemiological research are as follows. The first is that there must be an intention that justifies why the project qualifies as CS. Adherence to the ECSA ten principles can support such a justification. This is particularly important in being able to distinguish between CS activities versus traditional epidemiology with practices similar to those of CS (discussed in Section 2.2). The second is that intellectual input from citizens in more than one phase of the project should prevail over minimal civic involvement. The third is that CS can imply that citizens sometimes have a dual role, as both research subjects and active researchers, which should be clearly delineated

(discussed in Section 4).

This paper will primarily focus on co-created CS defined as a scientific project led by researchers together with the help of citizens who contribute throughout all stages of the research process. Citizens are in this case both decision-makers and producers of data. This paper does not suggest that the “productivity view” of CS is unimportant, but does propose that studies stemming from the “democratisation view” that align with a “co-created CS” objective present new opportunities and challenges for environmental epidemiological research.

## 2.2. Building blocks for citizen science in environmental epidemiology

Despite the novelty of CS in environmental epidemiological studies, public participation within this field of research is common practice. Over the years, research approaches in environmental epidemiology have shifted towards those that encourage input from both citizens and scientists (English et al., 2018). Developments such as open science, open data, open access scientific journals, and responsible science are general trends paving the way for CS (Majumder and McGuire, 2020, Hecker et al., 2019). Studies based on citizen's concerns in which stakeholders, including civic organisations, can contribute to discussions on research agendas via advisory committees have been present in environmental epidemiology for a long time (Haynes et al., 2011, Israel et al., 2005). Since the 1970s, “Science Shops” have flourished at universities, offering population groups access to scientific research (Leydesdorff and Ward, 2005). Other examples addressing civic concerns include studies on the effects of fine and ultrafine particle exposure from airports or intensive livestock farming and pesticides exposure in the Netherlands (Lammers et al., 2020, Post et al., 2020). All of these studies included various stakeholder's input via advisory boards. As more environmental health studies are collaborating with grass-root organizations, lay public and affected communities, research methodologies involving citizens are taking on diverse forms and labels such as community-based participatory research, participatory action research, crowdsourcing, volunteered geographic information, data donations, patient and public involvement, etc. (English et al., 2018, Roussos and Fawcett, 2000, De Marchi et al. 2017).

All these participatory forms could be interpreted as contributory, collaborative or co-created CS. However, we propose another way of distinguishing between participatory approaches and identifying where co-created CS stands within environmental epidemiology. Citizens primarily become involved in scientific research through either ‘participation’, ‘engagement’, ‘involvement’ or a combination of these three forms of inclusion as shown in Fig. 1 (adapted from Woolley et al., 2016).

‘Participation’ of citizens can take place both actively or passively and describes the process in which citizens become subjects in a study and primarily provide data (with or without their knowledge). This illustrates what contributory CS projects provide, that is, crowdsourcing and volunteered (geographic) information data collection methods to address the research questions defined by experts. In a study done to improve the impact of pollen concentrations, an online survey was conducted to monitor spatiotemporal variation in allergic rhinitis symptoms (de Weger et al., 2014). This example shows how the distinction between contributory forms of participation and the classical web-based epidemiological studies is small. Indeed, what Ekman and Litton, (2007) foresaw as “e-epidemiology” studies, which are studies conducted using digital media such as the Internet and mobile phones, is now an established practice in the field. In addition to being implemented in environmental epidemiology already, e-epidemiology or similar contributory forms of participation limit citizens' involvement to research subjects, excluding the possibility for citizens to be involved in the research process as scientists. However, it is important to highlight that present technological developments, enabling citizens to collect data regarding personal exposure, does play a large role in the re-found enthusiasm for CS projects (Balestrini et al., 2015).

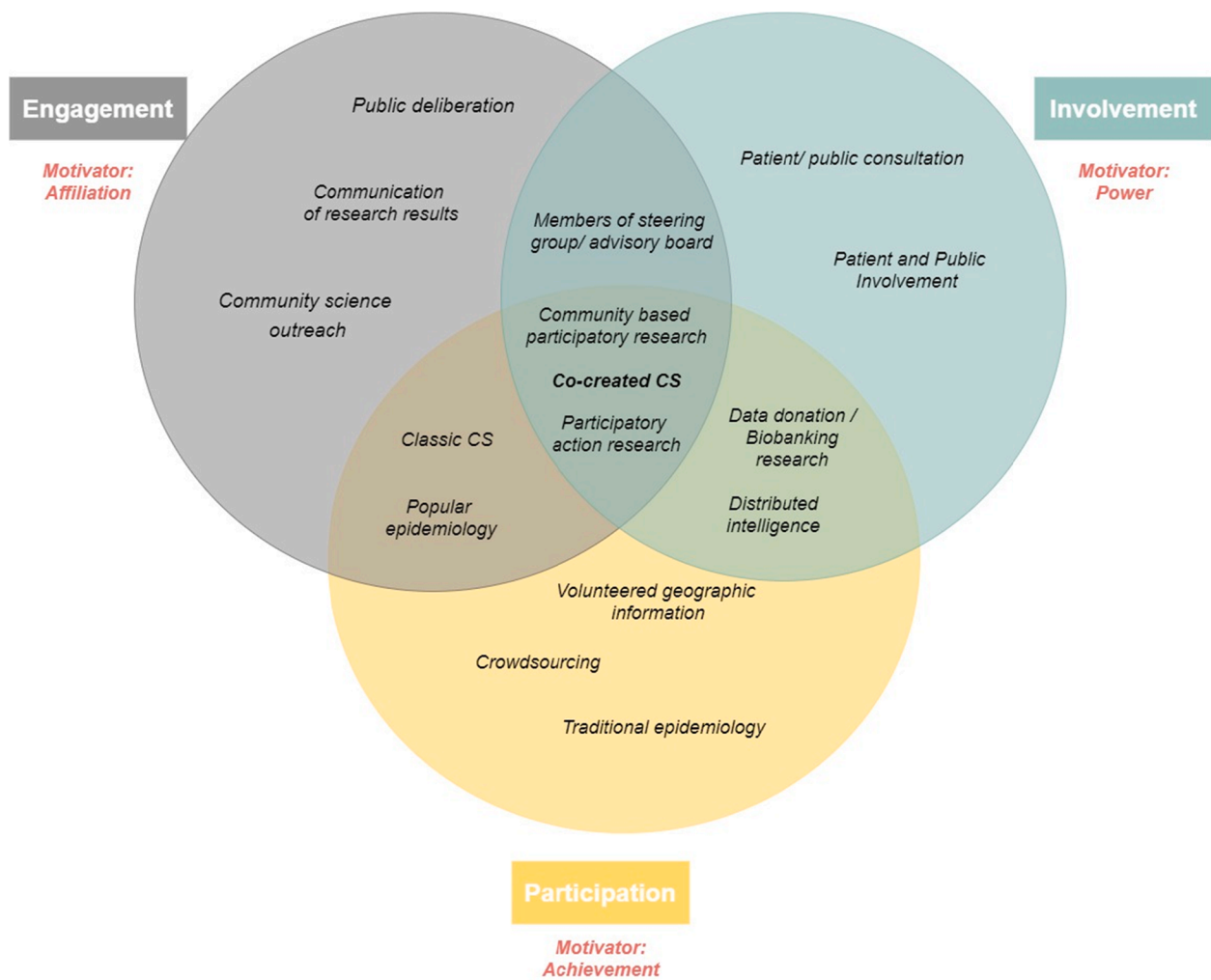


Fig. 1. Three main processes of citizen inclusion in environmental epidemiology, their intersections and their link with civic motivators. Venn diagram adapted from Woolley et al. (2016).

‘Engagement’ of citizens is closely linked to the exchange of knowledge and communication between citizens and researchers (Fig. 1). The more researchers communicate their research plans and request the public’s co-operation with this, the more or less engaged society becomes. Public engagement thus follows Bonney’s definition of CS, in which experts expose citizens to different aspects of scientific research in order to educate them, raise awareness and mobilise their support (Woolley et al., 2016). In environmental health studies, public deliberation and community outreach activities are examples of engagement practices that are frequently implemented (Judd et al., 2005, O’Fallon et al., 2003).

The intersection between the participation and engagement categories resonates with what was once described as popular epidemiology (Fig. 1) (Brown, 1992, p.267): “the process by which lay persons gather data and direct and marshal the knowledge and resources of experts in order to understand the epidemiology of disease, treat existing and prevent future disease, and remove the responsible environmental contaminants.” An example of this is the *Atenció* project in Barcelona (Projecte Atenció, 2020). This is an experimental study assessing whether air pollution in high schools can affect adolescents’ attention. In the design phase of the project, students were invited to propose a set of factors (confounders) that they believed could influence attention. Scientists then selected the main factors and created a final questionnaire. Meetings were organized to present and discuss the findings with the teachers, students and scientists. An example where citizens marshalled the knowledge and help of experts is Grechi and Biggeri (2016). In this case citizens mobilized

experts to conduct a grassroots investigation into the aftermath of an industrial accident. Nevertheless, such approaches do not imply active involvement from citizens in the study design and conduction since professional scientists remain the principal decision-making agents and keep control over how the research project is conducted.

The final way in which citizens can contribute to scientific research is through ‘involvement’ (Fig. 1). This category describes the active role of citizens in scientific governance, where citizens take part in problem definition, identification of research questions, study protocol design, data collection, data analysis and dissemination of study findings (English et al., 2018). In contrast to the public engagement category, public involvement is organised in a horizontal fashion corresponding to Irwin’s (1995) conception of CS where a deliberative and democratic relationship between experts and citizens is valued (Woolley et al., 2016). This category shares essential and similar principles to patient and public involvement in research, levelling out power differences between the public and health professionals and increasing the public’s ability to deliberate and influence research processes (Jackson et al., 2020, Imperial College Health Partners, 2014). Co-created CS supports this joint effort, but calls for equal involvement when it comes to decision-making processes. Environmental epidemiologists collaborating with members of the public outside academia and laboratories have the chance to develop better relationships with these communities. Allowing citizens to have a say in each phase of the project also helps in (re)gaining the general public’s trust in science. This type of research is strongly socially motivated, and is discussed in more detail amongst

environmental epidemiologists in Galea (2013) and philosophers in Buyx et al. 2017. Data donation- and distributed intelligence- based research are classified in the intersection between ‘Involvement’ and ‘Participation’. In comparison with crowdsourcing or traditional epidemiology studies, citizens can decide to contribute to research by giving researchers access to privately collected personal data, help create a collaborative dataset (data donation), or help perform data processing, analysis, and interpretation (distributed intelligence) (Bietz et al., 2019, Woolley et al., 2016). PatientLikeMe, is a platform where patients with different symptoms and conditions can share their experiences, and is an example of a patient-powered research network supporting clinical research by voluntarily submitting data for research (Wicks et al., 2010). Another concept that falls in this intersection is public biobanking. The Bioeteca Foundation in the municipality of Sarroch (Italy) where a large oil refinery is situated, is an example of an independent biobank owned by citizens, designed to improve the current environmental and health situation in Sarroch (Biggeri and Tallacchini, 2018). To get access to this biological data, researchers have to submit a research protocol after which citizens may agree to become involved by signing an ad hoc informed consent.

As shown in Fig. 1, most environmental epidemiological studies include at least one of the above-mentioned methods of public inclusion which are adjacent notions of contributory and collaborative CS. We believe that only when all three forms of public inclusion are met (participation, engagement and involvement), the research project can be considered co-created CS. Thus, when citizens collaborate with an environmental epidemiological CS initiative, they should be involved in most or all of the scientific inquiry process as both researchers and research subjects. A good example of a citizen motivated environmental study, is of two flood-prone communities in Atlanta who started to contact community-based organisations, universities, and governmental agencies to demand accurate data about potential health risks of flooding, such as the prevalence of asthma due to mould (Eiffert et al., 2016). Residents collected dust samples for quantifying mould contamination and were responsible for planning and implementing activities in response to the study findings.

Interestingly, community-based participatory research has a strong affinity with co-created CS. However, community-based participatory research is an approach adopted in environmental justice contexts to empower communities to address health inequities (Wiggins and Wilbanks, 2019, Eitzel et al., 2017; Temper et al., 2015). Participatory action research is another method that encompasses the participation, engagement and involvement categories within environmental epidemiological research. Participatory action research pays close attention to the power relationships between researchers and those researched (Baum et al., 2006), but in comparison with co-created CS, it focuses on action and problem resolution (Den Broeder et al., 2018). Another key difference with CS, compared to other participatory approaches such as community-based participatory research or participatory action research, is that CS does not necessarily require the input of experts and research institutions in a project. This type of CS, also qualified as collegial or autonomous, implies a maximum level of civic participation, engagement and involvement. The latter form of CS is gaining more and more traction due to citizens’ lack of trust toward experts. Through the use of social media scientific debates are becoming more polarized. In environmental epidemiology there are many examples of conflicts between citizens and scientific academia (Fjelland, 2015). Environmental epidemiologists are being called on to navigate these troubled waters and help restore civic trust. A story of an epidemiological investigation on a petrochemical plant framed into the complexity of the interface between epidemiology and society is in De Marchi et al. (2020).

### 2.3. A framework for CS in environmental epidemiology

CS covers a large diversity of topics and contexts, so a single one-fits-all model for CS in environmental epidemiology is not practical.

Presently, a number of general guidelines, toolkits, and participatory frameworks have been developed for the application of CS in environmental monitoring and environmental health (Kocman et al., 2019, King et al., 2016, Tweddle et al., 2012, Woods et al., 2018, ACTION Project, 2020, Briggs, 2008, English et al., 2018). These tools, frameworks and guidelines could either be adopted or adapted, to help both experts and citizens tackle the implementation of co-created CS throughout the different phases of epidemiological research. To explain how CS can be implemented throughout the research process, this paper will utilise the CityS-Health framework (Toran et al., 2019). This framework was designed for environmental epidemiological research from a general perspective, reflecting similar features that occur in the different participatory practices and highlighting the additional characteristics of a co-created CS project.

The CityS-Health framework was adapted from the Bristol Approach, a model of co-creation that builds on the principles of participatory action research, people-centred innovation and the common goods (Balestrini et al., 2017, The Bristol Approach, 2018). This is a well-established framework for the orchestration of CS interventions with the purpose of contributing to action, legacy and identification of citizens’ concerns as predominantly cross-cutting concepts. The premise of the CityS-Health framework is that co-creation with citizens occurs in all phases of the project. The framework comprises four phases: identification, design, deployment and action, as illustrated in Fig. 2. The phases are illustrated in a ribbon shape as these phases are not linear but take place and overlap throughout the duration of a research project. Firstly, during the identification phase, matters of civic concern regarding the topic of environmental exposure and health are identified and translated into research questions. Community building with involved citizens starts here and continues throughout the following phases. Secondly, the design phase entails the co-creation of data collection tools and data governance protocols. Next, the deployment phase encompasses data collection, data analysis and impact assessment. Finally, the action phase includes dissemination of results, co-created civic action that generates recognition for the issues explored during the project, and preparing the research project’s legacy. The knowledge and tools resulting from a research project should aim to be used and taken up by different actors of society to either replicate the project or raise awareness on the issues investigated. Policy recommendations or socio-technical infrastructure allowing other groups of citizens to replicate the study and contribute to new data are examples of legacy and sustainability. The concept of ‘sustainability’ in research will be explained in more detail in Section 3.1.

Even though the CityS-Health framework is able to provide practical guidance to environmental epidemiologists and corresponds to essential aspects of co-created CS, it does not represent a step-by-step plan that guarantees success. The sociocultural context of the issue investigated, resources available and civic expectations, needs and motivations, are examples of factors that can influence certain implementation phases. If researchers and citizens take the sociocultural context into account, everyone associated with the project will be more likely to benefit. Experts and citizens can also find inspiration from catalogues on CS research projects (SciStarter, 2020, EU-Citizen.Science, n.d., CitizenScience.gov, n.d., Bürger schaffen Wissen, n.d., EOS iedereen wetenschapper). These existing online platforms can be used to describe and share CS practices and experiences.

## 3. Rationales for citizen science in environmental epidemiology

### 3.1. Rationale for researchers

The impulse leading different scientific disciplines to take on CS as an additional approach is driven, among other things, by the array of opportunities that CS offers. Many authors have discussed the benefits of using CS for citizens and scientists in the realm of public and environmental health (Buyx et al. 2017, Den Broeder et al. 2018, English et al.,

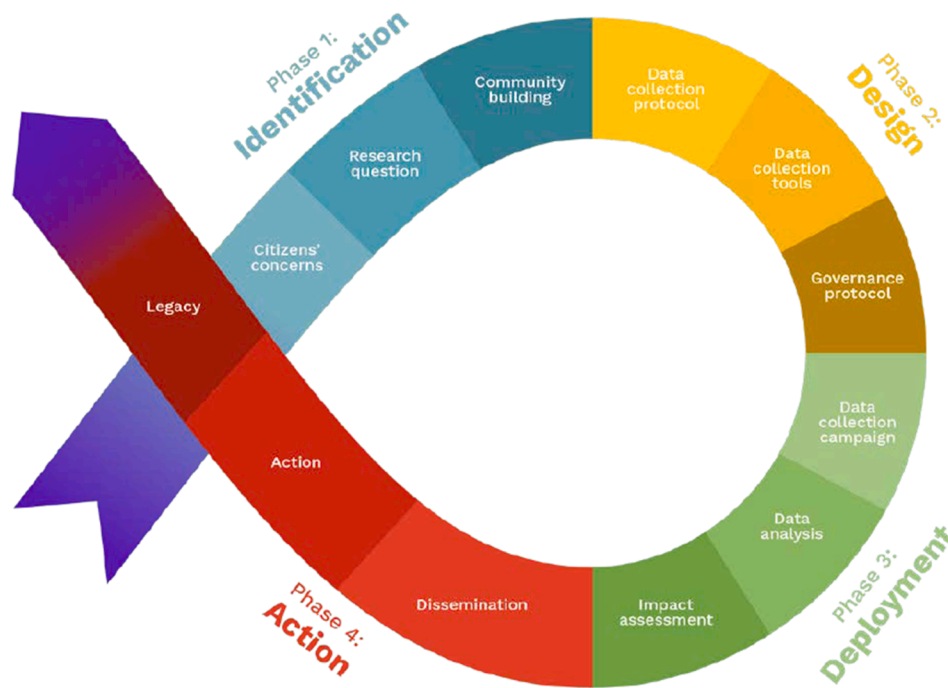


Fig. 2. The CityS-Health framework for citizen science in environmental epidemiology (Toran et al., 2019).

2018, Grossberndt and Liu, 2016). Depending on the broad rationale (democratisation or productivity view) in which CS projects are embedded, they will apply different forms and levels of public inclusion (participation, engagement and involvement), generating very different outcomes. This section shows that an environmental health study with a democratisation approach to CS can: (1) support the momentum of performing more socially relevant research; (2) foster more insights into the interpretation of problems and results; and (3) strengthen the dissemination of the findings while stimulating data-driven dialogue with policy-makers. Other more generic benefits of CS relevant to epidemiological research include increased research capacity, improved recruitment process and enhanced quality of participation, will also be briefly discussed.

**Support the momentum of socially relevant research:** Environmental epidemiological studies have progressively embraced more socially relevant, open and transparent research (Kramer et al., 2012, Weed and McKeown, 2003, O'Fallon and Dearry, 2002, Galea, 2013). These changes are being adopted by multiple researchers in the field through different participatory approaches, allowing co-created CS to become the point of reference for the ensuing research landscape, maximising the inclusion of citizens. Compared to the more common top-down approach where scientists refer to citizens or, more commonly, public policy needs in research proposals, CS is a more direct path towards more socially relevant research. Experts in environmental epidemiology have recognised that when setting research priorities, in addition to their scientific novelty, the relevancy of study proposals should be sustained by their societal significance (Weed and McKeown, 2003, Frumkin, 2015). Presently, most research agendas in environmental epidemiology are defined by scientists, policy-makers and/or pressure groups according to their interests and preoccupations (Hecker et al., 2019). However, the social relevance of these agendas are not usually judged by lay citizens themselves. This limitation is more relevant to studies focussing on location-based issues (e.g. citizens living near a chemical plant) than those tackling more generic issues (e.g. generic air pollution health effects). Consequently, priorities selected may not address the concerns of citizens living in that area. Co-created CS can help ensure a more locally-relevant and personalised research agenda, as citizens can add personal experiences providing local

knowledge regarding their community. Without civic input, this source of information is typically inaccessible to researchers.

**More insights into interpretation of results:** Environmental health problems are inherently multidisciplinary in scope. Currently, experts account for diverse effects that could impact citizens' health such as socio-economic status by incorporating them as covariates or modifiers. CS encourages experts to value and incorporate various civic perspectives into their research questions, study designs and results interpretation (Pykett et al., 2020). Citizens have shown that occasionally they are able to provide a more in-depth understanding of the data collected during a project than the experts. For example, in a noise study in Placa del Sol, Barcelona, Spain, citizens were able to explain peculiar data patterns due to personal knowledge of their living environment (Woods et al., 2018). Hence co-production of knowledge between citizens and scientists can lead to more diverse and nuanced interpretations of the results in studies (Tonne et al., 2017, Silberzahn and Uhlmann, 2015).

**Strengthening dissemination of results:** Environmental epidemiologists understand that their work may influence policy-making and government decisions in terms of reducing environmental hazards (Deener et al., 2018). However, experts may fail to effectively communicate their results to the public, making it difficult to understand the complexity of environmental health issues (Ramirez-Andreotta et al., 2014). Yet, when citizens become co-creators of research projects and produce their own scientific data to gain insight into problems affecting their environment, it galvanizes them into action and stimulates a data-driven dialogue with policy-makers. It encourages citizens to become ambassadors for local issues by sharing their results to influence local decisions and advocate for social change.

**Sustainable research:** CS projects often aim to create different outputs such as tools which can be re-used by the community to nourish a collective capacity in environmental health research. By actively involving citizens in co-created projects, scientists are able to: increase research capacity in terms of time and effort; improve participant recruitment and follow-up retention; enhance data collection and quality; enrich civic knowledge on issues investigated and strengthen the dissemination of the findings (Den Broeder et al., 2018, English, et al., 2018). Even so, these advantages of CS are more likely to be prominent in investigations regarding local environmental concerns.

Long-term viability of research projects is enforced by the sense of empowerment citizens develop throughout the research process. Researchers can catalyse the identification of unique research questions and local initiatives responding to environmental health issues through civic engagement. These benefits make CS a promising model to support environmental epidemiologists in their desire to create sustainable and responsible research. CS initiatives can help citizens in becoming 'scientists' to some extent and allows scientists to reflect on their role in local environmental health issues by understanding scientific concepts from a civic perspective.

### 3.2. Rationale for citizens

There has been considerable academic interest in environmental and public health studies to investigate civic motivators and perceived advantages to improve research attractiveness (Geoghegan et al., 2016, Bruyere and Rappe, 2007, Carrera et al., 2018, Lehman et al., 2020, Den Broeder et al., 2018). The following section uses McClelland's motivation theory to provide examples of the main generic reasons driving citizens to participate in research projects, including enhanced scientific literacy, greater ability to advocate for policy change and a stronger sense of community. After which motivators more specific to CS in environmental epidemiology, such as civic concern, will be addressed.

According to McClelland's motivation theory, driving motivators for citizens to participate in research could be placed in either one, or a combination, of the following categories; achievement, affiliation or power (McClelland, 1987). The driving motivator 'achievement' is similar to the 'scientific literacy benefits' in the analysis of Den Broeder et al (2018) of CS in public health. Citizens join because they can expect to increase their knowledge and understanding of epidemiological studies, experience the difficulties that come with conducting this type of research, increase their environmental awareness, and are provided the opportunity to learn new skills (e.g. environmental monitoring, group leadership) and abilities (e.g. process of self-reflection) (English et al., 2018). When the driving motivator is 'power', citizens want to transmit their values or influence others to take action in problems that are of concern to them. Whereas, 'affiliation' focuses on a citizen's interest to be part of a group with similar interests and beliefs (McClelland, 1987).

When comparing these driving motivators (affiliation, achievement and power) to the ways in which citizens can be included in scientific research (participation, engagement and involvement) we can identify some interesting links. If people are consciously interested in 'participation' one could assume that the motivator for this group of citizens would be driven by the motivator 'achievement'. Similarly, citizens interested in exercising 'power' within a study would apply to become a part of civic boards or civic research consultants, thus focussing on the 'involvement' sector of contribution. Lastly, citizens interested in 'affiliation' would be much more interested in the 'engagement' aspects of studies since they want to feel a personal connection with a group or organisation. We recognize that this link between the driving motivators and the citizens types of inclusion in research is not cast in stone. In fact, citizens could feel empowered when they attend different outreach activities or public deliberation organized by scientists (engagement), where others could find a strong sense of achievement by being involved in the advisory board (involvement). In comparison with research projects using more traditional or other participatory approaches in environmental epidemiology, projects choosing to use a co-created CS approach may have more opportunities to respond to a wider range of civic driving motivators.

A motivational driver unique to CS in environmental epidemiology is the opportunity for citizens to understand the link between the exposure to environmental hazards and health in their specific local setting. Curiosity is known to act as a motivational driver for people to volunteer or participate in scientific research. However, the motivation for citizens to participate in environmental health studies is often linked to actual

health concerns due to proximal exposures. Due to the latter, citizens are more easily mobilised to promote agency and enhance project community building. Den Broeder et al. (2018) suggested that CS in public health is an opportunity for citizens to actively contribute to solving problems or concerns they may have within their neighbourhood. The Curieuzeneuzen project illustrates a collective concern about traffic-related emissions that is far from a simple thirst for learning about exposure levels (Van Brussel and Huyse, 2019).

It is important to acknowledge the links between the driving motivators of citizens and the ways in which we currently allow citizens to contribute to research as they influence attraction and retention of citizens in research projects (Wright et al., 2015). Furthermore it can help researchers implement actions needed to stimulate collaboration. For example, giving certificates to citizens who join to achieve a new skill, or build a strong community network with personal connections for citizens who joined looking for affiliation to a group, or by inviting individuals who are interested in exercising power to lead certain initiatives.

## 4. Challenges in applying co-created CS in environmental epidemiology

Presently, CS approaches in environmental health studies are mainly descriptive in nature, oriented towards public health surveillance and based on environmental monitoring (Dixon et al., 2019, English et al., 2017, de Weger et al., 2014). In comparison to other disciplines, environmental epidemiology is unique in that it tries to determine a relationship between environmental exposure and health outcomes, in many cases with observational (i.e. non-experimental) data. Attempting to do this in a CS setting raises challenges. This section describes eight challenges that may play a central role in the application of co-created CS in environmental epidemiological studies (deduced from environmental monitoring studies): (1) the required expertise, (2) potential conflict of interest, (3) issues regarding available monitoring technologies and data quality, (4) data governance and ownership, (5) strength of conclusions drawn from single studies and civic expectations, (6) representativeness of participating citizens, (7) smaller study populations and (8) the need for ethical guidelines. A generic challenge highlighted in this section is the changing role of researchers and citizens.

**Required scientific expertise:** Technically, citizens are not dependent on research institutions to conduct CS research. However, collecting, analysing, and interpreting the data in an environmental epidemiological study requires certain expertise. Citizens would not only have to monitor environmental exposure and health parameters, but also analyse the possible associations between the exposure and health, whilst taking into account other potentially confounding risk factors. Understanding associations of a specific environmental exposure with health can be complex because there are typically multiple intercorrelated exposures and risk factors. Disentangling these factors may be challenging even for experienced researchers, let alone citizens without specialised training, knowledge or experience. The role of citizens in complex data analyses still needs further exploration, and we doubt whether autonomous or extreme CS projects without the help of scientific expertise are feasible in environmental epidemiology at this time. Partnerships between citizens and experts are vital since the use of local knowledge in projects is extremely valuable. Though co-creation throughout the research process is advised, this does not imply that citizens have to perform all steps in the research process. Nevertheless, researchers should explain and discuss all of the steps undertaken with citizens, which in itself is a major challenge that requires more careful attention. One important aspect to acknowledge in such a co-created scientific enterprise is the inherent uncertainty and incompleteness of any environmental epidemiological study. Participating in the production of scientific knowledge allows citizens and lay people to understand the complexity and limitations of epidemiological research. Limited

study size, selection biases, information biases and confounding, menace the validity of the results that make it difficult to interpret them with regard to the study objectives. Moreover the citizens' objectives or expectations may not correspond to those of the researchers and this collaborative approach will permit continuous confrontations between them. Researchers have their own conflict of interests and are sometimes prone to play different uncertainty strategies. When stakes are high, decisions are needed even when uncertainty is high (Funtowicz and Ravetz 1993).

**Conflict of interest:** Up until now ethics committees have only been concerned with the conflict of interest stemming from researchers, but with CS, citizens can also play a major role in this regard (Resnik and Elliott, 2016). In Section 3.2, citizen's rationales for CS, we highlighted that citizens may join projects to address an issue, or contribute to action or change within their communities addressing a subject of concern to them. Citizens who have a personal interest in the outcome of a study can interfere with how the project is perceived in terms of objectivity and trustworthiness (Shamoo and Resnik, 2014). If citizens are affiliated with pressure groups, political parties or (non-profit) organisations, conflicts of interest are likely to arise (Resnik et al., 2015). An example of biases resulting from the interests of concerned citizens is that they may tend to report their health outcomes in agreement with their perceived exposure experiences, also known as "awareness bias" (Moffatt et al., 2000). It is not new for environmental epidemiological studies to find that individuals expressing concern over an environmental risk are more likely to report symptoms (Roht et al., 1985, Claeson et al., 2013, Moffatt et al., 2000, Martens et al., 2018). However, these types of biases may increase if a project is predominantly driven by a worried group of citizens. Minimising such biases can be done by tackling them in the study design, a standard practice in epidemiological studies. Examples of the latter include: combining objective (measured) and subjective (self-reporting) methods (Moffatt et al., 2000, Martens et al., 2018); pre-specifying data analysis plans before data collection; checking participants' response consistency; disclosing all possible conflicts of interest, and providing transparency on these matters throughout the project (Resnik et al., 2015). Similar biases can affect environmental epidemiologists, leading to incomprehension and distrust in citizens. Unveiling experts' biases can help avoid situations where citizens refute the results, contest the study design, demand an independent evaluation of the study, or the conduction of a new study. Conflict of interests can also be viewed as the consequence of mismatches between researcher's aims and citizen's perspectives. Co-creating the study objective is thus an opportunity to unveil conflicts of interests within researchers and citizens.

**Data quality:** One generic data issue in the CS literature that applies to environmental epidemiology is data quality (Riesch and Potter, 2014, Resnik et al., 2015). Scientists worry about the lack of experience and formal scientific training among citizens (Buyx et al., 2017), which could lead to poor data quality, sampling error, and other biases. For instance, poor data quality may arise when low cost-sensors are applied with often limited validation (sensing devices and smartphone applications) (Kocman et al., 2019, Riesch and Potter, 2014, Resnik et al., 2015). However, CS does not imply that projects need to use low-cost sensors, it suggests rendering monitoring practices more accessible to citizens. Multiple authors have proposed practices to enhance credibility and ensure data accuracy including expert validation and employment of statistical modelling of systematic error, having advisory boards composed of scientists with relevant expertise and providing training sessions to citizens (Kosmala et al., 2016, Buyx et al., 2017, Freitag et al., 2016). Studies comparing the quality of data produced by citizen scientists and professionals have suggested that the reliability of CS data depends on the projects study design, training intensity, and how data is managed, analysed, and interpreted (Feldman et al., 2018). We note that by involving citizens data quality could also be improved, as it becomes more feasible to obtain improved spatial coverage of a study area, as well as provides more in-depth knowledge which can explain peculiar

data.

**Data governance and ownership:** Data ownership should also be discussed in detail with citizens to negotiate agreements and recognize all possible stakeholders' interests (Resnik et al., 2015). Though the research conducted may benefit all citizens involved, it is important that the benefits are evenly distributed. All citizens should be given scaled recognition appropriate to their contribution (e.g. possible co-authorship on publications or co-investigator status on grant applications). Currently, there is still a clear need for the creation of governance structures with contributions from both citizens and researchers (Biggeri and Tallacchini, 2018).

**Single studies and civic expectation:** A common issue in epidemiology is that a single study cannot provide definitive conclusions about the causal roles of a specific agent. Consistently, policy decisions for action are rarely made on the results of a single study. This can often be demoralising for citizens who join studies to get an answer to their questions and to implement change. When study results are not enough to guarantee change, this threatens civic motivation for research. This is also the case when prior civic expectations of study results versus the actual study results do not align. In our experience, citizens mostly expect the research to document the health effects they experience or anticipate. If the hypothesized effect is not found, or the strength of the association is weak, this can lead to frustration among citizens hoping to compile data to induce policy change (Fulton et al., 2019). Experts must clearly state that the results of the study may not meet the citizens' expectations during the onset of the project. This could be done, by discussing possible result scenarios and their policy implications, related strategies for communication and required action. In the scenario that an association is found, citizens and their interpretation of the results may be prone to exaggerated claims. To prevent misleading conclusions, the interpretation of the results needs to be correctly understood by citizens and explained by epidemiologists. Participating in the production of scientific knowledge allows citizens to understand the complexity and limitations of epidemiological research.

**Representativeness of the participating citizens:** Representativeness in epidemiology has always been a subject of debate among experts (Rothman et al., 2013). Currently experts agree that the appropriate selection of participants depends on the objective of the study (Rothman et al., 2013, Nohr and Olsen, 2013). In general, representativeness is not needed to design internally valid studies and we note that very few classical epidemiological studies are fully representative of the general population. Whether the scientific findings can be applied to the general population is a matter of judgment (Rothman, et al., 2013). When using a CS approach, population sampling is mainly volunteer-based resulting in experts working with specific population groups that have particular needs and preferences that are not necessarily representative of the broader population (Saueremann et al., 2020). In fact, the impact of CS in problem framing, agenda setting processes and on how projects are pursued, critically depends on the citizens that are involved. Since different views and interests exist in the population, research agendas may primarily reflect the preferences and assumptions of the citizens collaborating on the project. Consequently, if these views differ widely from large parts of the population, this may contradict the idea behind the "democratisation" aspect of CS (English et al., 2018, Mahr, 2014, Saueremann et al., 2020). CS projects in general have shown to attract a limited number of citizens, mainly middle-aged Caucasian men with higher levels of education and a pre-existing interest in science, or citizens who only briefly contribute to projects (Ganzevoort et al., 2017, Geoghegan et al., 2016, Haklay, 2013, Raddick et al., 2013, Van Brussel and Huyse, 2019). It is not obvious if this selection applies to CS projects regarding local environmental concerns, especially with respect to the factors gender and age. Nevertheless, studies have shown that when citizens work on projects of concern to them, their motivation to participate increases and so does study retention (Van Brussel and Huyse, 2019). We believe the responsibility to ensure inclusivity, when creating, designing and recruiting participants in a project with citizens,



resides with epidemiologists. To increase diversity of participants in terms of age, educational background, gender, ethnicity, cultural background etc. and reach out underrepresented population groups, epidemiologists should identify and reduce potential barriers related to language, location, technology and level of knowledge that make projects inaccessible. Examples of strategies to increase diversity include creating culturally sensitive recruitment materials, conducting recruitment activities in different community venues such as churches, grocery stores, daycare/community centres, etc. (Khubchandani et al., 2015). All in all, the issue of representativity and inclusivity should be discussed in a fully transparent manner with the citizens involved in the research.

**Smaller study populations:** Co-created CS requires some practical strategies to sustain the outreach activities whilst ensuring citizen's participation, engagement and involvement. Though it is not impossible to include a large group of citizens in a co-created CS project, this approach is better suited to small-scale location-based research with a relatively short duration. Thus far, successful projects have relied on a small number of citizens who contribute to most of the work (Sauer-mann et al., 2020, Franzoni and Sauer-mann, 2014). The time citizens are prepared to invest into a CS project, as well as the time in which it is feasible for citizens to collect data, can affect the duration and follow-up time of the study. Though in traditional environmental epidemiology large-scale research and long-term follow-up studies are valued more in order to measure small health effects, this does not imply that CS projects cannot produce useful knowledge. Firstly, well-designed studies with a modest scope can also produce worthwhile data and useful results, particularly on short-term effects making use of repeated measurements of the same individual. Secondly, larger local studies are feasible, if one distinguishes the two roles of citizens, namely that of subject in the study and co-researcher. In a co-created study it is not necessary and realistic to expect that all traditional subjects to become co-researchers.

**Ethical issues:** Only recently have the ethical issues concerning CS received any attention. Nevertheless, a number of ethical challenges relevant to CS in environmental epidemiology have already been discussed in the context of health and biomedical research (Kocman et al., 2019, Wiggins and Wilbanks, 2019, Resnik, 2019, Patrick-Lake and Goldsack, 2019). However, only a few ethical frameworks addressing these issues have been developed (Resnik and Elliott, 2016, Resnik et al., 2015, Riesch and Potter, 2014). The most distinct issue in the application of CS in environmental epidemiology (versus the application of CS in environmental monitoring) is the need to obtain medical ethical permission to perform the research. The issue can best build upon the already existing practice in medical research, but needs to be expanded on with specific CS issues such as the role of citizens as researchers and subjects in the actual conduct of the study. Guidelines on these are not only useful for experts but can also be used by citizens (Kramer et al., 2012) to help ensure proper research conduct from both experts and citizens as co-creators of the study.

Two generic issues that need ethical discussion are the dual role citizens play in CS research, and the link between CS and the open science movement. In CS research, citizens may have a double role in which they are both a member of the research team, whilst simultaneously taking part in the study as a research subject (Resnik, 2019). At the moment all the institutional ethical frameworks in place do not clearly accommodate civic role duality as both researchers and subjects. This novelty generates new responsibilities: the researchers' responsibility to communicate ethical standards with citizens involved in the study and the citizens' responsibility to comply with traditional ethical standards of scientific activity. Researchers and citizens will also be responsible for identifying and addressing new ethical aspects throughout all the research stages of the project. Moreover, the double role of citizens poses new challenges to the relationship between citizens and researchers such as, potential differences regarding information asymmetry, research integrity, and study outcomes. Considering the

current lack of legal recognition of the role of citizen scientists in research another notable challenge is a project's ability to receive ethical approval via the traditional scientific processes (Ficorilli et al., 2020). Though CS supports open sharing of data, including human health-related data (Robinson et al., 2018), Majumder and McGuire (2020) questioned this obligation and suggested that researchers should treat data sharing as an ethical requirement imperative to citizen autonomy. This means that citizens should be involved in the decision-making processes about the level of openness they are comfortable with. Determining the type of decision-making processes (e.g. consultative, majority, consensus) used in a project should also be discussed with citizens. Principal researchers of CS projects can consider including citizens in the development of the medical ethical protocol documents and invite citizens to sign off on the final product. Besides those mentioned so far, there are still various ethical issues (e.g. authorship, intellectual property, data sharing, etc.) that need joint deliberation between researchers and their ethics boards, which should include citizens in order to co-create guidelines suitable for the project and ensure ethical research.

**The changing role of experts and the balance between outreach and research activities:** Arguably, applying a CS approach can question the competencies, scientific autonomy and objectivity of experts. In this section, we do not adopt a view that challenges the role of scientists but describe difficulties epidemiologists may face. Co-created CS consists of a long engagement that needs to be continuously stimulated and reinforced through non-traditional scientific activities with participants, such as workshops, social events, and community meetings. Though it is not new for experts using participatory approaches to take on different roles such as popular educator or community organiser (Stoecker 1999), epidemiologists need to be trained to organise, manage, and conduct these activities successfully. If they are unable to do so they should partner with others that can provide complementary skills and knowledge.

Opening up research processes and sharing control and responsibility with non-professional citizens can collide with the norms of scientific autonomy supporting the expert's ability to make decisions related to scientific activities (Sauer-mann et al., 2020). Compared to government officials or elected representatives, citizen groups represent a more direct, targeted and perhaps, politicised influence shaping the direction of the research (Sauer-mann et al., 2020). Thus citizens need to find the balance between their politically-driven activism and being genuinely motivated to co-produce scientific knowledge. In the context where CS projects in environmental health touch on subjects that are socially, politically and economically charged, the position of the epidemiologist has to be better defined with regards to setting boundaries between empathy, activism, and objectivity (Brown et al., 2004, Wing, 2003, Zölzer and Zölzer, 2020).

A well-known challenge of CS for some researchers finding the right balance between the time and resources invested in research and those invested in engaging with citizens through outreach activities (Sauer-mann et al., 2020, Lakeman-Fraser et al., 2016). Currently, participatory research activities have mainly included benefits for scientists (large data sets) and policy makers/society (collectively gathering evidence and acquiring knowledge from non-traditional sources) (Lakeman-Fraser et al., 2016). Whereas outreach activities provide benefits for individuals (learning and training opportunities), scientific communities (promotion of science and expanding awareness) and society (changing public behaviour) (Lakeman-Fraser et al., 2016). Since the production of scientific publications is a common performance indicator defining research project success, there can be tension among experts arising from the time dedicated to other goals such as education and advocacy versus to the production of traditional research outputs (Sauer-mann et al., 2020, TNS BMRB, 2015). In this regard, a global effort and commitment is needed from academic stakeholders such as universities and publishers to assess research impact differently by going beyond the academic-oriented indices of research productivity and taking into

account the potential societal use outside the realm of academia (Curry, 2018, The Lancet, 2014). Currently, there has been some effort from funders, such as the European Union, by creating grant opportunities to entice researchers and academic institutions to incorporate CS components into their projects (L'Astorina and Fiore, 2017). These grants provide important funding opportunities for researchers and do not always require major alterations to existing participatory projects. Nevertheless, researchers need to address possible design conflicts that can arise when an existing participatory project incorporates CS at a later stage in the project and did not involve citizens at the start of the project.

## 5. Concluding remarks

Co-created CS has the opportunity to redefine the relations between epidemiology experts and the lay public, and transform the local production of knowledge into a more inclusive and sustainable process. That being said, the drive towards CS in environmental epidemiology does not mean that all epidemiological studies should include CS. Some questions may lend themselves better for classical epidemiological studies. Not all environmental epidemiological studies necessarily need to be "CS approved" to encompass the participation-engagement-involvement triad presented in this paper. Researchers are encouraged to consider how they can bridge the gap between science and society, by recognising that any civic collaboration is better than none. Articles in environmental health research claiming to be, or claiming to have applied CS, rarely share any information about how they applied CS in their research process. Consequently, this makes it difficult for experts to develop a cohesive comprehension of what CS means in environmental epidemiology and how to implement it accordingly. As such, we think it is important to encourage experts in the field to elaborate on how their studies were conducted with citizens via reports or scientific publications. This will help shed light on the co-creation processes needed to make CS a more tangible approach, and help develop a more complete ethical framework for CS in environmental epidemiology. Another way in which researchers can share information about their project is via a number of online CS catalogues. Further work is also needed to better prepare citizens for their inclusion in co-created CS environmental health studies via guidelines or co-design training sessions but also to better prepare epidemiologists for civic inclusion in the studies. This paper is one of the first attempts to thoroughly differentiate what CS entails in environmental epidemiology. Though CS bears commonalities with other participatory approaches applied in environmental health studies, it is clear that more inclusive research practices such as co-created CS yield a wider array of benefits for both experts and citizens.

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