# FUTURE DIRECTIONS FOR CITIZEN **SCIENCE AND PUBLIC** POLICY

Edited by Katie Cohen and Robert Doubleday Centre for Science and Policy

June 2021









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The Centre for Science and Policy was set up at the University of Cambridge in 2009 with the mission to improve public policy through the more effective use of evidence and expertise. CSaP does this by creating opportunities for public policy professionals and academics to learn from each other. CSaP has a unique network of over 450 Policy Fellows and 1,750 experts contributing to more dynamic and diverse scientific input to the most pressing public policy challenges.

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ISBN: 978-0-9932818-1-5

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# INTRODUCTION

### Foreword

### Sir Patrick Vallance

In June 2018, shortly after taking up my post as Government Chief Scientific Adviser, I was invited to speak at the Centre for Science and Policy's annual conference. I chose to talk about the significance of science to government, and offered some reflections on the relationship between science and policy, and on the importance of high-quality, relevant and timely science advice in improving outcomes for society and the economy. I argued that science must fundamentally aim to improve and enrich lives and keep people safe, and that in order to do this we must recognise that all citizens are increasingly both users of, and participants in, science.<sup>1</sup>

Since then, we have been through one of the most traumatic and impactful events of the last hundred years. The direct relevance to all our lives of science (in all its guises) has never been more obvious – not only in the way science advice has informed government decision making, and in the collective effort of the research community to develop diagnostics, treatments and vaccines, but also in the way we have all sought to shape and understand the impact of huge societal impositions and restrictions on health, wellbeing and the economy. This could not have happened without the collective participation of citizens across the UK and around the world; and it could not have happened without access to data.

From early on in the pandemic, we saw how crowdsourced data could help generate valuable insights into the spread of the disease, and this has only grown in importance. Later on, we saw large numbers of people participating in trials to identify effective treatments for COVID-19 and to test the effectiveness of vaccines. We were able to learn from our experience and from that of others, and to use this to improve and adapt our response. Without this level of engagement in science, it would have taken much longer to generate the evidence needed to understand what worked best.

The pandemic has shown clearly how, as citizens, we are all participants in science; and we are certainly all beneficiaries of its outputs. It has also demonstrated that although science is about knowledge creation and challenge, first and foremost it can help solve real problems and is relevant to all walks of life. We must not fall into the trap of thinking of science as an elite body of knowledge, understandable by only a few and beyond the reach of ordinary people. Professional scientists must reflect the diversity of the society they serve, and must also ensure that science is accessible and understandable to all. And as scientists in government, we need to work across boundaries, not content just to apply scientific method for its own sake, but framing problems in a way which enables us to develop solutions – solutions which can be understood and used by policy makers to improve outcomes for the citizen.

Often the knowledge needed to do this is already there. The ability to bring together evidence drawn from the current body of knowledge, in a way that is relevant, timely and built on excellence, is a critical element of the scientific process. To do this, science must be inclusive, rigorous, transparent and accessible, providing an opportunity for others to test, challenge and validate the conclusions. An absolute priority during the pandemic has been to ensure that these principles are embedded in the science advice provided to government, and that we learn and improve our ability to do this as we go along. And we need to recognise uncertainty, express it clearly, and indicate what is needed to try to address that uncertainty. This collection of essays embodies these principles, and demonstrates the many and varied ways in which citizen science can improve and enrich all our lives, delivering better science and better outcomes for all. I am very grateful to CSaP for bringing together this diverse group of authors to share their experience of citizen science, enabling us all to better understand the potential it has to contribute to public policy.

**Sir Patrick Vallance** is UK Government Chief Scientific Adviser (GCSA) and Head of the Government Science and Engineering (GSE) profession.

#### **Endnotes**

1. https://www.csap.cam.ac.uk/news/article-keynote-lecture-sir-patrick-vallance/

### Acknowledgements

The Centre for Science and Policy (CSaP) was launched in 2009 and has since pioneered new ways of bringing academia and government together to address public policy challenges. In spring 2019, in response to policy makers' questions about citizen engagement and public trust, we were keen to explore how a third voice could be brought into the conversation: the voice of the citizen. Fortunately for this project, CSaP was already working closely with two people who have gone on to help shape this collection. Anna Alexandrova, a philosopher of science, was leading the Expertise Under Pressure research project investigating the authority of experts. Jennifer Gabrys, an environmental sociologist, was working on new modes of citizen participation in environmental issues with a project funded by the European Research Council called Citizen Sense. The support of Anna and Jennifer and growing interest from policy makers in our network crystallised the opportunity for CSaP to explore the potential for citizen science to contribute to public policy.

Though we knew citizen science was a topical issue, we did not anticipate the traction it would gain as a result of the COVID-19 pandemic. Sciencepolicy relations have sustained newfound pressures over the past year, sparking further interest in citizen involvement in scientific and political processes. We hope this collection will raise awareness among policy makers about the success and variety of citizen science approaches, and point to concrete ways that citizen science methodologies can contribute to effective policy making.

This project would not have been possible without support from the Expertise Under Pressure research project at the University of Cambridge. We would like to thank Principal Investigator Anna Alexandrova, Project Administrator Una Yeung and the rest of the team for enabling us to take forward our interest in citizen science. We are grateful to THE NEW INSTITUTE for its generous funding of Expertise Under Pressure and the University of Cambridge Centre for Research in the Arts, Social Sciences and Humanities (CRASSH) for hosting it.

Over the last two years, CSaP has convened discussions that have raised many of the ideas that are fleshed out in this collection. We would like to thank Johannes Vogel, Director General of the Berlin Natural History Museum, whose CSaP lecture in Septmber 2019 helped raise awareness of ways citizen science could contribute to improving relations between science, government and citizens. The following table provides an outline of CSaP events that have culminated in this collection of essays.

### **CSaP Policy Fellows summer reception**

Date:	8 May 2019
Speakers:	Anna Alexandrova, Jennifer Gabrys, Susan Owens
Online resources:	www.csap.cam.ac.uk/news/article-continuing-policy-fellows- roundtable

# Citizen science: reshaping relations between science, government and citizens

Date:	23 September 2019
Speakers:	Johannes Vogel, Jennifer Gabrys
Online resources:	www.csap.cam.ac.uk/news/article-citizen-science-professor- johannes-vogel

### Innovations in Citizen Science for Public Policy virtual conference

Date:	24-25 March 2020
Speakers:	Alan Irwin, Muki Haklay, Jennifer Gabrys, Sarah Darwin, Michiel Van Oudheusden, Jessica Montgomery, Philipp Verpoort, Maike Weißpflug, Jason Chilvers
Online resources:	www.csap.cam.ac.uk/media/uploads/files/1/citizen-science-report.pdf www.csap.cam.ac.uk/news/article-what-are-citizen-sciences www.csap.cam.ac.uk/news/article-citizen-science-2020

### CSaP Annual Conference virtual seminar series: Citizen Science

Date:	28 May 2020
Speakers:	Jennifer Gabrys, Julie Pierce, Johannes Vogel
Online resources:	www.csap.cam.ac.uk/news/article-citizen-science-virtual-conference- seminar

# Citizen science for environmental policy making (collaboration with UNDP Argentina Accelerator Lab)

Date:	29 October 2020
Speakers:	Jennifer Gabrys, Gervase Poulden
Online resources:	www.youtube.com/watch?v=_DuFsAU3f6c

### CSaP Policy Fellow seminar series: Citizen science

Date:	February-June 2021
Speakers:	Authors and Policy Fellows
Online resources:	www.csap.cam.ac.uk/news/article-planets-policy-citizen-science- zooniversewww.csap.cam.ac.uk/news/article-data-governance-21st-century- role-data-trustswww.csap.cam.ac.uk/news/article-principles-practice-why-citizen- science-so-hardwww.csap.cam.ac.uk/news/article-citizen-science-beyond-grassroots 

These events were made possible with the support of Jackie Ouchikh, Hannah Williams and Kate McNeil at CSaP. CSaP Policy Interns Julia Amtmann, Samuel Ward and Matthias Meller have also made significant contributions over the past academic year to event organisation, editing and overall development of the collection.

We would also like to extend our thanks to those who have been involved in the production of the collection: Mike Green at Green Doe Graphic Design for the design and printing, and Nick Gray for the copy-editing. Finally, we would like to express our sincere thanks to all our authors. Without their insight, enthusiasm and support this collection would not have been possible.

#### Katie Cohen and Robert Doubleday

May 2021

## Future directions for citizen science and public policy: Introduction

### Katie Cohen, Robert Doubleday and Matthias Meller

It's late in the afternoon when she returns from the early shift, and an email pops into her inbox. The pandemic is raging, and she's exhausted from an anxiety-filled day at the maternity ward, looking after the nervous future mothers under her care. The subject line reads, 'We need your experience now!' It is a rapid-response research project about protecting patients and NHS staff from infection during obstetric emergencies. She follows the link, pleased to be able to contribute her perspective on managing COVID-19 cases in pregnant patients for everyone's benefit.

Each day, in this otherwise quiet corner of a London borough, the peace is periodically interrupted by a stampede of lorries barrelling down his narrow road. Though he lives on a quiet street, he doesn't feel comfortable sending his kids off to walk alone to school because of the traffic congestion. After writing to his local councillors and MP to no avail, he jumps at the opportunity to participate in a digital sensing project to monitor air quality around his home.

As a graphic designer accustomed to working with powerful tools, she's always keen to see how complex tasks can be translated into digital interfaces. So when she hears on the news that software to analyse NASA's Kepler space telescope images is open source, she's eager to try it out. Logging onto Zooniverse, her mild curiosity about a tool to help find new exoplanets soon turns into enthusiasm for discovering them herself. A year from now, she will not only be one of the platform's most active contributors, but also the co-author of several scientific publications.

These people are more than just proactive and engaged citizens – they are what we call 'citizen scientists'. Citizen science characterises a set of practices that cut across neat distinctions between professional and amateur, between facts and values, between experts and lay people. Consequently, the term provokes equal measures of curiosity, hope, confusion and suspicion. The OED tells us that citizen science is "scientific work undertaken by members of the general public, often in collaboration with or under the direction of professional scientists and scientific institutions." However, even this definition raises many questions for policy makers trying to figure out how they might make use of it: "What is the difference between a volunteer in a scientific study and a citizen scientist?" they might ask. "Are all forms of public engagement with science considered citizen science?" or "What does it look like in practice?" – or even "Why do I need to bother engaging citizen science at all?"

This collection of essays presents a range of perspectives on these questions, and we hope it will encourage greater use of citizen science by governments. The authors have been brought together by the Centre for Science and Policy (CSaP) through a series of seminars, lectures and an online conference. Three observations were made time and again:

- First, there has been an extraordinary flourishing of citizen science during the past two decades. Huge numbers have participated in projects ranging from spotting patterns in protein structures to monitoring local air pollution; from garden bird surveys to deciphering the handwritten notes from the archives of philosophers; and from tracing radioactive contamination to spotting new planets in distant galaxies.
- Second, there is a growing imperative in government to find new ways to involve citizens as partners in the development and delivery of policy.
- Third, that while public funds have supported the expansion of citizen science's contributions to scientific research, there have been surprisingly few experiments drawing on citizen science to contribute to the business of government itself.

This introduction to the collection sets the scene by outlining the background to diverse practices that are encompassed by the term citizen science. It then describes (and gives some initial responses to) three

common challenges levelled at citizen science, namely about the quality of data; about the representativeness of findings; and about the practicalities of scaling up for use by governments. Each essay is then briefly introduced in the context of the overall purpose of this collection. Finally, we invite people working in government to consider finding out more about how modest experimentation with citizen science approaches could open up new ways of generating evidence, and of building productive relationships with citizens.

# A brief history of citizen science: from fossil collecting to COVID-19

The activities that characterise citizen science are by no means new.<sup>1</sup> Before science became a formalised profession during the nineteenth century, people would use scientific methods to try to answer puzzling questions about the natural world. Dating back to the British colonisation of the Americas, citizen scientists such as founding fathers George Washington and Benjamin Franklin collected and recorded data to predict storm patterns and other weather events. In seventeenth-century England, naturalists such as John Ray recruited volunteers to collect specimens for his experiments. By the Darwinian era, public participation in fossil collecting and botany was commonplace, and to this day phrenological observations still make up some of the longest-running citizen science data sets.<sup>2</sup> Other fields like astronomy, ornithology and butterfly counting have also long attracted amateur scientists.<sup>3</sup>

These early examples of citizen involvement in science paved the way for what we now know as citizen science. As Muki Haklay discusses later in this collection, research and other scientific institutions have drawn on citizen-volunteered data and expertise for over 150 years. From William Whewell's great tide experiment of 1835 and the Meteorological Office's weather observation since the 1850s, the UK has a long history of engaging public participants in formal scientific endeavours. Citizen science also has roots in the efforts of people who feel themselves to be suffering from the state's failures to protect their wellbeing – for example, the farm workers exposed to organophosphates (and the union that represented them) collecting evidence to campaign for recognition of their case, as described by Alan Irwin in his seminal book on Citizen Science in 1995.<sup>4</sup> The story of innovation continues into the current century: OpenStreetMap launched in 2004, and today is used by tech giants such as Facebook and Microsoft; Open Air Laboratories (2007-2019) has contributed to science education; and the Zooniverse platform, established in 2007, has reached well over one million volunteers.

It is the COVID-19 crisis, however, that has put the complex relationship between science, government and citizens centre stage. In a peak moment of scientific and political uncertainty, scientists worldwide have steadily illuminated patches of the unknown, modelling transmission and developing vaccines. At the same time, it has become clear that 'following the science' will not suffice – that, as Sheila Jasanoff told us early in the pandemic, science alone will not come to the rescue.<sup>5</sup> Navigating the uncertainty has required more than sophisticated modelling and convening of experts. It has required judgement to weigh necessarily incomplete, and sometimes conflicting, evidence against political objectives.<sup>6</sup> Public trust in political decision making and science advice has become paramount, especially as public adherence to government regulations has proved necessary to emerge from the crisis.

The Winton Centre at the University of Cambridge conducted a study to see how the COVID-19 pandemic has impacted public trust in science and policy.<sup>7</sup> Although public trust in scientists has remained steady over the course of the pandemic, trust in policy professionals and politicians has declined. This is not surprising, given the pre-pandemic trend of declining trust in national government detailed in a British Academy report on the long-term societal impacts of the pandemic.<sup>8</sup> The report states: "Pre-pandemic measures of trust show a high level of disenfranchisement with both the systems and figures of governance, painting a picture of a nation that is 'actively at odds with the sense that the central governing system is serving their needs and reflecting their voice."

However, the report goes on to say that trust in local governments and organisations has remained stable, and they therefore have a crucial role to play in ongoing responses to the pandemic. Even once the vaccine campaign was underway and a timeline for lifting lockdown was put in place, "54 per cent [of the population] doubted the government's competence whereas only 21 per cent doubted their local council's competence." This dichotomy between trust at the local versus national level leads us to believe that the public is more likely to trust decision-making processes if they feel those processes are closer to them and more responsive to their experiences and concerns. Citizen science is one mechanism by which people may feel their understanding of the world has a chance to be listened to and taken into account by powerful institutions.

Citizen science has in fact proved to be a crucial interface over the past year. Efforts to contain the spread of the virus have relied both on collecting population data and on building mutual trust between citizens, scientists and decision makers. Citizen science projects have popped up in many countries, engaging people who are motivated to help understand the virus and its impact across dimensions beyond the data dashboards.<sup>9</sup> Citizen science platforms and networks have adapted to harness this moment of increased interest, adding resources to engage with COVID-19 research.<sup>10</sup> In the UK, the ZOE COVID Symptom Study – a collaboration between King's College London and NHS England – has been the most widespread citizen science effort to track the virus.<sup>11</sup> In summary, during the COVID-19 pandemic, citizen science has gained greater recognition in the UK, the EU, and globally.

This unique moment in science policy and citizen science has further encouraged CSaP's efforts (which began in 2019)<sup>12</sup> to explore how citizen science can play a more significant role in public policy making. How, then, have we defined citizen science for the purposes of this collection of essays? We convened a workshop in March 2020 to consider 'What are citizen sciences?' – reaching the conclusion that it is preferable to consider a plurality of practices than to confine ourselves to a narrow definition.<sup>13</sup> Alan Irwin proposed thinking of citizen science as a means of tapping into 'citizen knowledges', a conceptualisation we would like to adopt in this collection.<sup>14</sup> While many forms of public participation are standard practice in public policy, including voting and public consultation, we are particularly interested in forms of participation grounded in the knowledge which citizens bring to the policy-making process. We hope this collection of essays will demonstrate that citizen science can provide notable benefits for science, government and the public in various forms, whether it be a crowdsourcing exercise, citizen assembly, co-produced experiment, or formal academic study.

As it turns out, it is not just academics and practitioners who advocate for a broad definition of citizen science. A European Citizen Science Association (ECSA) study set out to address areas of definitional ambiguity by developing a set of characteristics of citizen science.<sup>15</sup> A survey including various examples of citizen science activities was sent to representatives from both within and outside the research community, including selfidentified citizen scientists. The resulting characteristics represented a broad spectrum of activities classed as citizen science, and included statements calling for plurality.

By collating citizen science case studies and perspectives, this collection shares insights about how citizen science can improve the process of policy making. These lessons apply across policy domains that are current UK priorities, including data governance, biodiversity and climate change, food safety and security, wellbeing and health.

In making the case that citizen science can facilitate and improve scienceinformed policy making, however, we also recognize that there are concerns about the applicability of citizen science that deserve attention. Governments have evolved established practices for drawing on public views, scientific evidence, and the analysis of policy options; these practices are governed by a mixture of legislation, institutional structures and administrative habits. As the stakes can be high and opinions divided, decisions are closely scrutinised and decision makers may be called to account for their actions to parliament, courts and the public. It is therefore understandable that policy makers will ask tough questions of any new approach to informing decision making.

With respect to the promise of citizen science, three questions have repeatedly been raised: Can we rely on the quality of evidence that citizen science generates? How representative of the population as a whole are its contributions? And how practical is it for governments to support citizen science as part of policy making? We consider each of these in turn.

### Quality: robustness and reliability of evidence

Evidence gathered through crowdsourcing and other citizen science methodologies is often assumed to be of poorer quality than expertgathered data. The reliability of citizen scientists' outputs is frequently called into question because it is presumed that they lack the rigor of professional scientific outputs, and it is thought that the participating citizens may have 'an axe to grind'. Given the choice, policy makers will often prefer standardised and validated data from the professional scientific community.

At the same time, some scientists are wary of public involvement in research, as they fear this could risk the hard-won trust placed in evidence produced by science. In his essay in this collection, Muki Haklay reminds us of the institutional and cultural barriers at work here: deeply embedded practices of the scientific community are challenged to be made accessible by 'outsiders', stirring up concerns over whether citizen scientists bring the 'right' motivation to research, and deeper currents of fear about diminishing the social standing of science (with implications for continued public support).

Citizen science literature has approached this issue in a number of ways. Gwen Ottinger points to standards as an obstacle to citizen science efforts, and endorses strategies that focus on adopting standardised practices to make citizen science data more credible.<sup>16</sup> Employing the same method used by regulators and industry – in her example, the use for bucket monitoring of the TO-15 method for sample analysis – can lend credibility to citizen-gathered data, and has the potential to ally citizen scientists with regulators. Margaret Kosmala and her colleagues urge the consideration of citizen science datasets on an individual basis, as projects are increasingly relying on a suite of methods to reduce bias and boost accuracy – with demonstrable accuracy when compared to professionals.<sup>17</sup> Meanwhile, Jennifer Gabrys has advocated for citizen-gathered data as 'just good enough data', showing how citizen science can challenge usual ways of producing, valuing and analysing datasets.<sup>18</sup> The US Environmental Protection Agency (EPA), amongst other environmental regulators, has endorsed supplementing data from government monitoring stations with low-cost digital sensors, because they can provide more 'indicative' air pollution measurements, revealing patterns in data.

In this collection, authors expand on these approaches to the question of data quality as they pertain to specific case studies. For instance, citizen science has produced reliable evidence in response to sudden or emerging events such as the COVID-19 pandemic or the nuclear accident in Fukushima, as Michiel Van Oudheusden, Ruth Kern and Christian Reynolds and his colleagues discuss in their essays. The ability of citizen science to amass large sample sizes and produce rapid results makes it especially suited for crisis response in periods of extreme scientific uncertainty.

Citizen science has also contributed greatly to the robustness of evidence by ensuring that scientific knowledge is relevant to the local circumstances of citizens. For instance, Michiel Van Oudheusden points to knowledge gaps regarding local variations in vulnerabilities, personal protection measures and infection rates, and notes that "[a]lthough the techniques used by citizen scientists may fall outside the usual best practices for validating these types of data, they can be 'just good enough' to point out knowledge gaps and to bring about policy action where and when it is most needed." Christian Reynolds and his colleagues illustrate the importance of this benefit of citizen science in the food policy sector. Citizen science methods enable data to be collected on an ongoing basis from areas that are difficult for professional scientists to access, such as food consumption within the home. Since food plays an important role in people's daily lives, citizen science can prove a particularly effective way to "co-collect a wider range of robust information on household behaviours, and help to understand priorities for people based on their lived experience."

Concerns about the reliability and robustness of citizen science are understandable, especially as its methodologies are relatively new entrants into the policy making world. As the essays in this volume demonstrate, we should not expect there to be a single simple answer to these concerns. The relevant question is – what can citizen science add to the evidence gathering process? In answering this question, it is important to be clear about the purpose to which knowledge is being put. It may be that citizen science can harness engagement with issues that matter to people in their local community, but which are not currently captured by more formal scientific processes. In this way, citizen science could be used to sensitise and inform standard evidence gathering processes, as well as extend their reach.

### Representativeness: approaches to diversity and inclusion

Governments round the world are grappling with how to achieve diversity and inclusion in decision making. This is not a new problem – but the potential of increased public participation as a way of achieving these goals is gaining renewed attention. Various forms of citizen science offer innovative ways to harness citizens' knowledge, such that decisions may more fully represent the populations they affect.

During discussions convened by CSaP, government officials have repeatedly referred to the risks of voluntary processes ending up giving voice to 'the usual suspects', as compared to systematically gathered data using representative sampling techniques. The concern these officials are pointing to is well documented; unless care is taken, volunteers for citizen science projects are likely to be more affluent, older and have higher educational qualifications than the population at large.<sup>19</sup> However, essays in this collection illustrate the active steps that that citizen science experiments can take to ensure more diverse and representative participation; and while citizen science does not by its nature ensure inclusion, it can be a helpful tool for broadening the scope and sources of evidence feeding into policy decisions.

The question of representativeness is explicitly addressed in citizens' assemblies, a form of citizen science which has gained popular acceptance as a way of democratising policy processes. In Philipp Verpoort's case study of a citizens' assembly on transport policy in Cambridge, he comments on the assembly's selection process: individuals are selected randomly "to represent the diversity of the population in terms of age, gender, ethnicity, educational background, and most frequently used mode of transport." He claims this "representativeness and diversity of the members" is one of the key advantages of citizens' assemblies over other forms of public consultation. One may argue that there are other critical factors to consider when thinking about diversity (such as disability status and income level), but citizens' assemblies certainly do give voice to perspectives often underrepresented in policy making processes. Environmental policy questions appear particularly suited to the use of such deliberative democratic methods, where (as in this example) local perspectives on public transportation routes, cycling paths, and other interventions have filled gaps in decision makers' knowledge.

The COVID-19 crisis has made the need for the inclusion of diverse voices in policy decisions even more apparent. Governments worldwide have been criticised for neglecting under-represented communities that have been most severely affected by the pandemic.<sup>20</sup> In her essay, Ruth Kern outlines the efforts that THIS Institute has made over the past year to connect with participants through their online citizen science platform Thiscovery. She explains how online methods can engage with under-represented groups (such as shift workers and people with caring responsibilities), and offer a range of opportunities for more or less time-intensive participation, thus attracting larger sample sizes overall – though it remains important to offer alternative modes of engagement to avoid excluding groups without internet access or literacy.

### Practicality: mobilising sustainable infrastructures

Another persistent question for those who wish to include citizen scientists in shaping public policies is how to move beyond one-off projects, and integrate this form of expertise into existing governance structures. Alan Irwin tells us that citizen science can often *"sit uncomfortably between technical evidence and public consultation"* and is therefore not readily digestible by current policy processes. Several of the essays in this collection consider ways in which this integration might be achieved.

Chris Lintott and Ruth Kern help us understand the importance of accessible and user-friendly platforms to link participants to programmes. Indeed, Lintott makes the argument that access to the same data ('open data') and ideally the same tools as the professional scientists is vital not only for motivating individual contributors to engage, but also for increasing the sophistication of the results. Open data and open source tools are, of course, not new considerations in debates about governance and public administration in an era of 'digital transformation'. However, these experiences of engaging citizens effectively in research projects shed light on how to scale and sustain public involvement in policy making.

In reflecting upon the COVID-19 pandemic and how to build better futures in its aftermath, many policy conversations have focused on the potency of infrastructures. The pandemic has shown us how much the world depends on a digital infrastructure supplied by only a handful of companies – while data relevant for policy making, much of it concerning consumer choices and citizen preferences, is held by a disparate set of public and private entities. Jessica Montgomery and Neil Lawrence introduce us to the concept of 'data trusts', infrastructures maintained by independent intermediaries that act in the interests of their members to contribute citizens' data to policy making in an accountable fashion. By these means, citizens have a voice in these processes without surrendering democratic representation in decisions over data use. As the authors explain: "Complementing the regulatory regimes that already exist in many countries, these new 'bottom-up' institutions would seek to empower individual citizens to influence the terms under which data about them may be used." Great hopes are being placed in infrastructure investments to build more sustainable and equitable futures for citizens, such as the multi-trilliondollar investment plans announced in early 2021 by US President Biden. Jennifer Gabrys reminds us that infrastructural projects are often assumed to be positively transformative in and of themselves, and thus in their early planning stages frequently do not involve public input. However, as she argues, citizen engagement is vital because these infrastructures are not just technical artefacts for citizens; they are systems that co-exist with citizens and shape public life.

### **Outline of collection**

The essays that follow offer new ways for governments to think about citizen science. They demonstrate varying cultures of engagement, and consider what kinds of citizenship might be encouraged by the greater adoption of citizen science approaches.

The first section includes theoretical and practical perspectives on involving citizens in the policy-making process. **Alan Irwin**'s essay begins by framing citizen science as a distinct form of scientific advice for government. **Chris Lintott** then examines a successful Zooniverse project in which citizen scientists contributed actively to new scientific discoveries, and draws lessons about the motivation and resources needed for citizens to contribute their knowledge more effectively to policy making. **Anna Alexandrova** concludes this section by arguing for the co-production of scientific research (in this case, wellbeing research), breaking down the traditionally unidirectional relationship between science and the public, to instead engage citizens from the outset.

Next, we turn to case studies of citizen science initiatives across different policy domains, asking what factors enabled or hindered their success in engaging decision makers and the policy making process. **Michiel Van Oudheusden** looks at grassroots initiatives in Singapore, Taiwan and South Korea during the COVID-19 pandemic; he analyses why these efforts successfully contributed to government decision making, and argues for the better integration of citizen science in crisis management. Christian Reynolds, food policy experts and collaborators at the Food Standards Agency then share practical examples for food policy makers looking to integrate citizen science practices into existing structures of governance. Philipp Verpoort demonstrates how citizens' assemblies on environmental policy debates have proved effective in engaging diverse groups of residents in local environmental decision making. Ruth Kern concludes the section by underscoring the importance of intermediary institutions in mediating the relationship between citizen scientists and policy makers, and explains how THIS Institute has validated citizen science practices in healthcare improvement research over the past year.

The third and final section of the collection examines examples of participation that activate new forms of citizenship – demonstrating the possibility of promoting citizen engagement in policy making even within more resistant institutional cultures. **Jennifer Gabrys** draws on her work in environmental citizen science to discuss the democratic potential of different forms of participation. **Jess Montgomery** and **Neil Lawrence** consider data trusts and their potential to engage citizens more actively in the governance of their data. Finally, **Muki Haklay** reminds us of the institutional and cultural resistance that citizen science must overcome to contribute more effectively to policy making, charting a way forward for UK policy makers navigating such hurdles.

### A new decade for citizen science

Although there are systemic barriers to integrating citizen science more fully into the scientific and policy processes over the next decade, there are signs that the tide is turning in favour of increasingly participatory forms of governance. Just last year, UK Research and Innovation awarded £1.5m to projects that integrate citizen techniques into research methodologies.<sup>21</sup> At the same time, the European Commission Horizon 2020 programme's launch of the EU-Citizen.Science platform – a hub for citizen science projects, resources, tools and training – also marked an important development in knowledge sharing between citizen scientists, researchers, practitioners and policy makers.<sup>22</sup> These are just a few of the signs that citizen science is gaining traction not only in its existing community, but also at higher levels of governance.

Over the past year, CSaP has convened many discussions on the potential for citizen science to contribute positively to policy making processes. Supported by the Expertise under Pressure research programme at the University of Cambridge,<sup>23</sup> these conversations have often sparked more questions than answers – but they have also supported our hypothesis that more and better public participation in science and policy is desirable. Despite this, governments still seem to approach the idea with reticence.

Our position is not to lay out a prescribed way of working, but rather to illustrate the benefits of a more comprehensive set of participatory practices which we include in the term 'citizen science'. We invite you to consider citizens as knowledgeable and motivated contributors to science advice and policy, and to embrace the thinking and approach to citizen science laid out in this collection. We hope this collection will begin to chart the way forward for integrating citizen science practices into public policy.

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1. DEMOCRATISING SCIENCE AND POLICY

**Citizen science and public policy making: A thought experiment** Alan Irwin

From planets to policy Chris Lintott

**Citizen science and wellbeing** Anna Alexandrova

# Citizen science and public policy making: A thought experiment

### **Alan Irwin**

I want you to make an assumption and then consider the consequences. It will only take a few minutes, I promise.

Imagine that citizen science can make a positive contribution to policy making. Since time is short, let me simply say that by citizen science I mean the kinds of knowledge actively developed by people who are not formally recognized as experts: usually, outside scientific institutions. Examples can be found in many areas – birdwatching and beekeeping, pollution tracking and starwatching, healthcare and agriculture – with 'citizen data science' a growing phenomenon (not least in the COVID-19 pandemic).

Many benefits have been claimed for citizen science. On the one hand, it unleashes a huge societal resource and empowers citizens in new ways. On the other, it can ask fresh questions, open up perspectives and data sources, and offer a very robust form of 'public testing' with regard to policies and practices. Of course, I do not mean to sing the praises of each and every example of citizen science. There are real challenges here, not least in removing barriers to community engagement. But remember that this is a thought experiment.

There are many important questions to raise and many issues to discuss. However, for now let us simply assume that citizen science – at least some of the time and in some ways – can help make better decisions about matters of public policy. Here then is my question. Given the assumed benefits of citizen science, how do we think that it actually connects with current policy processes? How in practice does that happen?

There is much more to citizen science than can fit within the 'technical advice' category. However, since this is a thought experiment, we should try to keep things simple. Currently, technical advice flows into public policy making in many ways: scientific advisory committees, chief scientists, technical civil servants, regulatory bodies, technical papers and reports, commissions, pressure groups, consultancies, think-tanks, informal networks, personal contacts, meetings and discussions of different kinds. Also, although many scientists complain about it (at least sometimes), the power of the media and online communications cannot be ignored.

The thought experiment concerns how citizen science can find a place within all this. When it comes to policy making, who or what speaks for citizen science?

Asking the question is not meant to deny the effect that citizen science already has on public policy. There are good examples of that – and the current pandemic supplies even more. Instead, the purpose is to ask how we can make that link more effective, and in a manner which does not simply incorporate it within the standard processes of scientific data collection. Are we confident that citizen-based evidence, reflection and reporting on healthcare improvement, food systems and environmental matters (to take just three examples) will feed into public decision making and action? In practical terms, what processes and procedures need to be put in place?

I can imagine several reactions. One rather 'classic' response is to argue that good evidence will prevail. There are multiple sources of policy expertise and no single mode of information flow. Why should citizen science be treated any differently? There is merit in this argument for openness and impartiality. However, the problem is that it risks ignoring the particular sociological characteristics of citizen science. The fact that citizen science can be informally organised, exists (often) outside the conventional institutions of science, and is not necessarily designed to fit with scientific standards of proof, in many ways represents its strength. However, in policy fora, this can make citizen science seem partial, anecdotal and hard to handle when set alongside more conventional forms of expertise.

A second response is, very reasonably, to question my implicit model of the policy process. Policy happens at many different levels and can be emergent as well as planned; in other words, there is much more to policy making than happens in national advisory committees and formal procedures. Perhaps citizen science can more easily assist in some fields and at some levels than others?

This is a valid point. Certainly, we can imagine that some kinds of citizen science – for example, as developed by patient groups, food producers, or area-based environmental groups – will have greater weight at a local and immediate level. Perhaps this is less a matter of providing advice than building sustainable and trusting relations between a range of parties. However, that does imply leaving many areas of policy making beyond the reach of citizen science.

A third response takes my basic premise at face value in order to ask how the flow of citizen science into policy making can actively be improved. This is the kind of discussion I am keen to encourage.

And now what were just described as the 'sociological characteristics' of citizen science come back into view. Citizen science can, at least for policy makers, sit uncomfortably between technical evidence and public consultation: is this primarily an expression of science or of citizenship? Citizen science takes many forms, some more digestible by current policy processes than others. Quality control keeps coming up as an issue, even if 'quality' always involves a judgement about what to value and from whose perspective. In this case, we tend to hear more about the scientific quality of specific initiatives and projects than we do about the citizenship equivalent. We have to acknowledge too that citizen science can have an unsettling effect on professional civil servants and acknowledged experts: *"are you saying that someone without a single scientific qualification knows better than me?"* It is clear that an essential aspect of citizen science's 'coming of age' is that policy makers need to reflect on the uses, benefits, difficulties and possibilities of citizen science.

There is a challenge in linking citizen science to policy – not always, but in many cases. However, the responsibility for this cannot all be placed on citizen science. The question then is whether, instead of fitting citizen science into established policy processes, we should think about the kinds of policy process which can make the most of citizen science. That at least is where this thought experiment leads us.

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Acknowledgements: I am very grateful for the helpful referees' comments on an early draft of this article and also to Maja Horst (DTU) and Sine Zambach (CBS) for their input. Special thanks to the CSaP Policy Fellows who took part in an online discussion of these ideas in April 2021.

## From planets to policy

### **Chris Lintott**

An increasingly common form of citizen science project involves the distributed labelling, sorting or classification of data by an online crowd. The first successful examples, such as Stardust@Home,<sup>1</sup> appeared in the physical sciences, though they are now common in disciplines as diverse as history and cell biology. The Zooniverse platform, established in 2019, hosts more than 100 such projects, including Penguin Hunters<sup>2</sup> – which recently provided data to inform the setting of boundaries of a marine protected area.

Aggregated data from this type of project can therefore be seen to influence policy. However, ambitions for citizen science interactions with policy often go beyond the provision of useful data. Projects such as the Parenting Science Gang<sup>3</sup> enable citizen scientists to set their own research agenda, at least partly with the goal of influencing health policy through dialogue with experts and institutions. In this paper, I draw on a case study of volunteer-directed research in the Planet Hunters project to consider by analogy how Zooniverse-style citizen science projects might promote direct engagement with policy. Citizen scientists writing their own papers on new discoveries is, in this analogy, the equivalent of the Parenting Science Gang's policy engagement, in contrast to the more conventional route, as seen in Penguin Watch, where citizen science data informs policy only via a professional scientist's work.

### **Planet Hunters**

The Planet Hunters project<sup>4</sup> allows volunteers to search for planets around stars other than the Sun, using data from NASA's Kepler and TESS satellites, which monitor the brightness of hundreds of thousands of stars. Volunteers identify candidate transit events, where the star's light is dimmed by the passage of the planet in front of it. While this task is eminently approachable with automated methods,<sup>5</sup> visual inspection can be rewarding; Eisner et al.<sup>6</sup> report the contributions of 22,000 registered volunteers, presenting 90 planet candidates which had not been previously reported.

The present incarnation of Planet Hunters is built on the Zooniverse's Panoptes platform,<sup>7</sup> and in keeping with the vast majority of Zooniverse projects it presents data to volunteers in a constrained fashion. Volunteers cannot choose which star's data to review, and must use a limited set of tools to mark features of interest. Following classification, volunteers can comment on what they have seen via a custom-built 'Talk' system.<sup>8</sup> This system provides structured discussion around the subjects of classification (in the case of Planet Hunters, these are graphs, each showing one star's brightness over a set period of time) within a searchable interface. Talk may be accessed either directly after classification, or by searching or browsing.

### Serendipitous discovery in Planet Hunters

Talk has been responsible for enabling the discovery by volunteers of numerous unusual objects which could not be classified via the primary interface. The most well known example is Boyajian's Star,<sup>9</sup> which displayed dramatic and unpredictable changes in brightness that were unusual enough that the presence of alien megastructures around the star was seriously considered as an explanation.<sup>10</sup> The star's distinctive nature was first recognised and discussed on Planet Hunters Talk by the citizen science community, who used ancillary data from NASA's archives to form and test hypotheses as to the nature of the object. Only after this discussion was well advanced did the professional scientists of the Planet Hunters team become involved.

It is common for Planet Hunters discoveries to begin on Talk, rather than through analysis of data submitted via the project's main interface. The recent publication of two planets in orbit around a nearby Sun-like star, HD 152843, includes as co-authors the citizen scientists who took part in a discussion of the system.<sup>11</sup> As the project has progressed, a proportion of participants have become increasingly sophisticated in their ability to contribute to exoplanet science.<sup>12</sup> This has led to collaborations between citizen scientists and professional scientists beyond the Planet Hunters team. For example, two planets in the WASP-47 system were identified by citizen scientist Hans Martin Schwengeler via the Planet Hunters project, and his detections were confirmed by a professional team.<sup>13</sup>

Research projects have also been initiated by the Planet Hunters community, rather than led by professionals. An example is the discovery of features which probably correspond to the transits of exocomets (rather than exoplanets) in Kepler data of the star KIC 3542116.<sup>14</sup> This discovery depended on a search for such features carried out by citizen scientist Tom Jacobs using the LCTOOLS software, itself produced by a citizen scientist, Allan Schmitt.<sup>15</sup>

Jacobs and his colleague Darryl LaCourse have published their own catalogue of single transit events in data from the second phase of the Kepler mission,<sup>16</sup> and are co-authors on more than 20 refereed papers. For these volunteers, citizen science efforts initially carried out via the constrained interface of Planet Hunters have led to full participation in the astronomical community overwhelmingly dominated by professional astronomers.

### From planets to policy

In this paper, I want to draw an analogy between this process – where initial engagement via a specific project leads to a broader engagement at a more technical level – and that by which citizen scientists, such as those engaged in environmental or ecological work, might come to influence policy and policy makers. Such influence is a matter of communication and collaboration between such actors and the citizen scientists, rather as citizen scientists carrying out advanced work in exoplanet searching have had to find a way to communicate with their professional peers. Similarly, professional scientists who wish to collaborate with citizen scientists are in an analogous position to policy makers who seek to incorporate the practice of citizen science in their methodology.

In order to become a participant in self-directed research, or a citizen scientist engaged in advocacy or in policy processes, one requires motivation and access to resources. I will deal with each of these factors in turn, beginning with motivation.

It appears that the motivations of participants in Zooniverse projects are primarily to do with 'making a contribution'. An early survey, for example,<sup>17</sup> found that the most common motivation for participants was 'contributing to science', rather than pursuing a prior interest in the relevant scientific domain. This is also seen in user behaviour; when, for example, the Snapshot Serengeti project, having received sufficient classifications for their purposes, announced that further input would not be processed, traffic to the site dropped even though volunteers could still review images from the camera trap network. It seems that contributing data is important, and that volunteers are willing to work within a constraining interface to achieve this. A more recent survey found that participants recognise that the interface does not give them the freedom to explore fully, but they do not feel that their autonomy is undetermined; this effect is not detrimental to their satisfaction.<sup>18</sup> These results suggest that few, if any, volunteers start work on Planet Hunters because they anticipate wanting to write their own exoplanet papers (even though the goal of the project to which they are contributing is to discover planets and announce them through the writing of exoplanet papers).

By analogy, we should be wary of concluding that participants in citizen science projects where the overall goal is to influence policy necessarily want to influence policy themselves; their participation is likely to be motivated by interest in participation per se, rather than a desire to contribute directly to higher-level goals. However, this is not to say that the 'standard' mode of interaction with Planet Hunters does not play a role in the emergence of volunteers undertaking advanced tasks. The primary project acts as an 'engine of motivation', stimulating interest and motivating users to learn more advanced means of interacting with data. By providing an accessible way to begin interacting with data, Planet Hunters increases the pool of potential advanced volunteers. Likewise, the number of people who are potential actors in the policy sphere may be greatly increased by participation in citizen science projects in relevant domains.

If the goal of a project is to increase the likelihood of citizen scientist interaction in the policy process, concentrating on providing an accessible 'first step' which greatly increases the number of potential policy actors is likely to be more useful than building advanced tools, or designing a complex project which directly addresses policy. Such an advanced project may empower those who are already interested, but it will not create mass participation from those whose goals at the outset may not lead them to want to invest time in learning complex tasks. Because only a small portion of those who participate in projects will choose to (and be able to) go on to broader 'citizen science' careers, increasing the size of the initial pool is important.

The existence of a large pool of newly motivated volunteers is not unique to Planet Hunters – indeed, it is shared across many Zooniverse projects – but only Planet Hunters has seen the emergence of a community with the capability and agency to carry out independent work of such range and quality. (Though note the development of advanced forms of analysis of data from the LIGO gravitational wave observatory by participants in the Gravity Spy project, which was designed to deliberately foster such interaction.<sup>19</sup>) What, then, is special about Planet Hunters, and what can we learn from it?

#### The importance of openness

Like other astronomical citizen science projects, Planet Hunters draws on a scientific domain where data sharing and open data practices are extremely common. The potential of this combination was revealed by the first large-scale distributed citizen science project, Galaxy Zoo, which inspired the Zooniverse; the discovery and subsequent analysis of the 'Green Pea' galaxies by the volunteers of the self-organised Peas Corps<sup>20</sup> was an early example of the kind of advanced work later displayed in Planet Hunters. Other astronomical Zooniverse projects, such as the Milky Way project, have also seen successful volunteer-led or inspired investigation of anomalous objects and classes of object.<sup>21</sup> Astronomical projects which do not provide access to metadata such as co-ordinates which allow volunteers to carry out follow-up work, such as Supernova Hunters,<sup>22</sup> do not develop a community of advanced practice and have not produced serendipitous discovery.

Can we explain why, of all those projects where open data existed, Planet Hunters became most successful in encouraging work beyond the core interface? The answer is extrinsic to Planet Hunters itself. The Kepler mission which provided data for the project until 2018 saw significant investment in tools for analysis, and in support for a rich archive of data. Open source software such as Lightkurve<sup>23</sup> is used by professional and citizen astronomers alike. Archives such as MAST and the Exoplanet Archive (funded by NASA and hosted at Johns Hopkins' Space Telescope Science Institute and Caltech respectively) provide web-based tools for exploration and analysis which significantly lower the barrier to participation in exoplanet science compared to other areas of astrophysics.<sup>24</sup> Especially during the extended mission, when data from the satellite was open-access instantly, these tools were materially important in increasing the number and geographical range of those working with Kepler data. Despite being designed primarily around the needs of professional scientists (and funded for this purpose), this ecosystem of tools later enabled citizen scientists to work alongside their professional peers.

In considering Planet Hunters, we therefore see that the existence of citizen science projects to motivate participation is necessary but not sufficient for communities of advanced work to flourish. Open data and – critically – the availability of an open toolset matter too. The Planet Hunters project's wide reach and accessible interface produced a large community of motivated citizen scientists, who were able to go further if they chose because of the existence of the exoplanet toolkit described above.

In seeking to extend citizen scientists' influence over policy, we therefore need to ask what a policy-related equivalent of such a toolkit would be. It would enable citizen scientists to make their own exploration of data, whether derived from projects they had participated in, or drawn from elsewhere. It would exist not within a citizen science project, but be used by established actors in policy; situating such tools in a space shared with those who already participate in policy processes would allow citizen scientists and their work to become incorporated more easily in existing formal structures. Ultimately, clear documentation and openness from those setting policy is likely to be more effective in opening up policy making to citizen scientists than any intervention rooted in the citizen science projects themselves.

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### **Citizen science and wellbeing**

### Anna Alexandrova

The idea of a citizen science – that is, production of knowledge designed and carried out by members of the public, sometimes in collaboration with professional scientists – is not universally accepted, and at times may be genuinely controversial. But my focus here is on an area in which some kind of citizen science is simply not optional and should not be controversial at all; on the contrary it should be normal. This area is wellbeing.

Wellbeing research is an interdisciplinary project on the social, economic, and psychological causes of flourishing, with the goal of helping individuals, communities, and organisations to promote it. My message is that because wellbeing is a value-laden concept, the responsible way to measure it is by involving the relevant stakeholders in the process of definition and quantification.

Wellbeing is what philosophers call a thick concept;<sup>1</sup> it describes as well as evaluates. To ascribe wellbeing to an individual or to a community is to give relevant empirical information about their lives, but it is also to evaluate them – because it is impossible to know which empirical information is relevant to wellbeing without making a value judgement about what it means to fare well, to flourish, or to thrive. This thickness means that any study of wellbeing depends on the two pillars of facts and values, and while scientists can conceivably claim to be expert on some facts, expertise about values and about value-laden facts is much more complicated. To know what values should guide measurement of wellbeing requires a systematic and comprehensive evaluation of what matters to us. When we are talking about individual wellbeing, this evaluation is intensely personal; equally, when we are talking about community wellbeing, this evaluation should ideally take the form of an inclusive deliberation, where the members of a community come together to decide what matters to them.

When the science of wellbeing got going in earnest three decades ago, it was dominated by psychologists and economists, who understandably brought their own methods to eliciting these values. Psychologists devised surveys about happiness and life satisfaction, while economists cross-compared the results of these surveys to various indicators they already worked with. The conceit has always been that if we figure out what questions to pose to people (that being considered an entirely technical issue), then, whatever answers we get, these answers properly reflect people's priorities. This has always been the main justification behind life-satisfaction surveys ('How satisfied are you with your life as a whole?'), whose proponents claim that these surveys are maximally democratic because in asking a very general question they allow people to identify and to weigh their priorities. They contrast life-satisfaction measures to multidimensional indicators of quality of life, which can only be summarised if an expert decides which weights should be assigned to each of the dimensions. So the advocates of life satisfaction surveys do not feel the need for a citizen science of wellbeing, because according to them citizen priorities are already at the heart of the whole exercise.

I submit that this is an impoverished vision of what it means to involve people in science. It is a vision driven by priorities that are altogether technocratic: the goal is to collect well-behaved data with a single number representing individual wellbeing, then to aggregate and regress these numbers against available official statistics and to direct spending where it gets most wellbeing for the cost.<sup>2</sup> The ambition behind modern happiness economics and positive psychology is often humanistic, i.e. to redirect public spending towards more mental health services and to equip people to deal with the stress and anxiety of modern life. However, the modus operandi of these fields is that 'experts do wellbeing to people'. In these studies people are never asked whether their rating on a one-to-ten scale represents their wellbeing, nor what it means to them, nor whether the most cost-efficient policies accord with their priorities. This is why I believe there is scope here for genuine citizen science, where citizens are not just being surveyed, nor even administering surveys that experts have decided suit their purposes on technical grounds. Citizen science of wellbeing should co-produce new measures in collaboration with the communities this science is supposed to serve. It could probably do even more (such as co-produce wellbeing policies), but let me illustrate just this first step.

In collaboration with a national poverty charity Turn2Us, Mark Fabian (Bennett Institute for Public Policy, University of Cambridge) and I have been exploring a genuinely participatory approach to wellbeing. We are co-producing a conception of thriving that specifically fits the stakeholders of Turn2Us, i.e. people experiencing sudden financial hardship. Our model is to assemble three groups of experts: the lived experts who know what it's like, the charity workers in charge of the funds, and the academic experts with knowledge of wellbeing research. Through a series of interviews and workshops, especially designed to share power and responsibility, we are discovering, first, what thriving means to each group and, second, what practical indicators can be used to track it at Turn2Us. The emergent theory is multidimensional and rich. While it is not wildly different from other conceptions of wellbeing that emphasise basic needs and personal growth, the co-produced theory is nevertheless distinctive enough to convince us that this process was necessary and that no 'off-the-shelf' questionnaire would fit the needs of Turn2Us.

We are certainly not the first to try such a co-production exercise. Engaging patient groups is standard practice in healthcare research, and national bodies all over the world, including the UK's Office of National Statistics, have conducted numerous consultations about what wellbeing means to the publics they are serving. But these approaches often cannot afford the intense dialogue and the deep exchange that our participatory model enabled, and hence the results they produce are often platitudinous –

pleasure matters, money can't buy happiness, and so forth. While they are better than life-satisfaction surveys, consultations and focus groups are still fundamentally expert-driven and hence do not live up to the spirit of citizen science.<sup>3</sup> We are trying to do better. It is unusual work that takes us academics out of our comfort zone, but the outcome is a measure of thriving with unprecedented democratic legitimacy for Turn2Us.

We are sometimes asked what the point of such a small-scale exercise is. The point lies in the very process that respects different forms of knowledge about thriving. If the price of co-production is a construct of wellbeing that fits only a specific context, then in my book it is a price worth paying.

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# 2. CULTURES OF ENGAGEMENT

**Citizen science in pandemic times: Lessons across east and west** Michiel Van Oudheusden

**Citizen science for the food system** Christian Reynolds, Libby Oakden, Sarah West, Rachel Patemen, Chris Elliott, Beth Armstrong, Rebecca Gillespie and Michelle Patel

**Citizens assemblies as a form of citizen science: A case study from Cambridge** Philipp Verpoort

Using citizen science to respond to the policy challenges of the COVID-19 pandemic: A case study from healthcare improvement research Ruth Kern

### Citizen science in pandemic times: Lessons across east and west

### Michiel Van Oudheusden

In dealing with the COVID-19 virus, East-Asian countries such as Singapore, Taiwan, and South Korea continue to win global praise. However, while the success of these countries is frequently ascribed to decisive government action, effective contact tracing, good risk communication and civic compliance, the contribution of citizen science and related grassroots initiatives in tackling the pandemic often remains largely obscured – or is even wilfully ignored. This essay considers what can be learned from these initiatives, and how they can inform public policy, scientific research, decision making and public engagement with technology both in East Asia and in the West. It argues that the emergence of citizen projects in these regions is revealing of the possibilities and limitations of democratic civic participation in politically volatile and uncertain times.

According to the official data, East-Asian countries have done comparatively well in managing the COVID-19 pandemic. The number of infections, deaths, and hospital admissions due to the virus remains significantly lower in Singapore, Taiwan, South Korea, and Japan than elsewhere in the world.<sup>1</sup> International institutions such as the World Health Organisation continue to praise the public-health policies implemented by East-Asian governments, as do other expert bodies and authoritative voices.

Singaporean officials have repeatedly hailed their country's COVID approach – which is based on extensive testing, effective information campaigns, and vigilance – as a model for others to follow, not only because it saves many lives, but also because it limits the economic repercussions of the virus outbreak.<sup>2</sup> Taiwan also comes in for praise from observers for taking measures at an early stage to stop the virus from spreading and wreaking havoc on a large scale; and South Korea is lauded for how it controlled outbreaks without having to resort to a full lockdown, using knowledge gained from previous epidemics.<sup>3</sup> More recently, journalists have pronounced Malaysia 'the latest Asian success story,' arguing that unlike Westerners, East Asians heed the advice of their governments and prioritise duty to society over selfish, individual needs.<sup>4</sup> As these illustrations suggest, the consensus among experts is that East-Asian countries are handling the crisis relatively well thanks to decisive government action, sound expert advice, stringent contact tracing and testing, civic obedience, and strong healthcare systems.<sup>5</sup>

There is, however, more to the story than official data and expert reasoning shaped around simplistic binaries (East/West; prepared/unprepared; collectivist/individualistic). To fully grasp the success of East-Asian countries, we should not focus exclusively on the top-down strategies of government experts and policy elites, but also consider how citizens and local communities have organised their own responses to the COVID outbreak, with or without the help of formal institutions.

#### Lessons from previous crises

In early 2020, when early warnings began to emerge about a virus outbreak in the Chinese city of Wuhan, I was staying in Tokyo. I was immediately struck by how many people wore face masks, how everyone kept their distance, and how regularly they disinfected their hands with sanitiser – omnipresent in tidy Japan.

But even more striking to me were the allegations of complacency quickly voiced by the Japanese against their own government. Citizens complained about the lack of personal protective equipment for those who needed it most. The government had promised to provide two face masks for every household; but this falls short for an average Japanese family consisting

of two parents and one child. They also took issue with the lack of testing capacity and poor government communication, which brought back unpleasant memories of the 2011 Fukushima Daiichi nuclear meltdown, when the authorities failed to provide timely and accurate information to the public about the spread of radiation. Stressing the need for rapid reaction, Safecast – an international citizen science organisation in Tokyo that emerged in response to the Fukushima accident – published a set of best practices in reference to COVID-19 for citizens, government, and media based on previous lessons.<sup>6</sup> On 23 March, the group also launched a crowdsourced COVID-19 testing information map, documenting people's experiences such as their symptoms and whether they were able to get a test when they sought one.<sup>7</sup>

Similar responses can be observed in other East-Asian countries. with citizens taking matters into their own hands when appropriate. In the South Korean city of Daegu, the first coronavirus epicentre outside China, shop and restaurant owners closed their businesses pre-emptively to help avoid a nationwide spread of the virus. Citizens' prior traumatic experiences with SARS (severe acute respiratory syndrome) in 2003, H1N1 in 2009, and MERS (Middle East respiratory syndrome) in 2015 played a major role in this collective decision, and helped to expedite the government's COVID policy based on strict quarantine implementation, expansive hightech tracing technology, and easy access to tests.<sup>8</sup> Despite the enduring perception of a lack of transparency during the SARS and MERS outbreaks (when South Korea's government kept important information hidden from the public, including data about the number of contaminated patients and where people were being hospitalised), and despite also continuing social suspicion about the government's surveillance efforts, there is evidence of a gradual restoration of public trust in government policy.<sup>9</sup> Part of this success can be attributed to the fact that South Korea put new coordinating institutions in place after MERS in 2015.

The same can be said of Taiwan, where this approach allowed the country to act even before the first confirmed COVID case on 21 January 2020.

In Taiwan these institutions include a Center for Disease Control and the Taiwan FactCheck Center. The latter is an independent fact-checking organisation run by citizens, journalists and researchers with the aim of countering disinformation; it urges citizens to verify dubious information in the news and on social media and refrain from sharing it until its authenticity is checked, and has published several reports based on citizens' contributions. Significantly, it was set up in collaboration with the Taiwanese government with the aim of boosting public confidence in Taiwan's crisis management response.<sup>10</sup>

By contrast, many citizens in Hong Kong remain disappointed about the government's management of past epidemics and distrustful of the authorities in general. In 2015, local communities felt obligated to take their own safety precautions, such as regular hand washing and avoiding crowded places and gatherings.<sup>11</sup> Here, as in other illiberal contexts, citizens are driven to develop their own coping strategies independently from government – perhaps even turning citizen science into a 'protest technology' along the way.<sup>12</sup> An example of such a technology is HKCoronavirus Cases on Kaggle, which encourages citizen scientists to use the data science platform Kaggle to unearth patterns in publicly available data about the virus outbreak.<sup>13</sup>

In Singapore, public criticism takes its own distinct form – as does citizen science. Despite extensive testing, the city state overlooked significant clusters of COVID-19 cases, primarily in housing complexes with migrant workers; and although this issue appears to have been resolved, some Singaporeans have publicly questioned the government's discriminating pandemic response, and have raised concerns that the virus could strike again, or may manage to gain a strong foothold in the country after all.<sup>14</sup> Notably, the government has mobilised the rhetoric of citizen science, openness, and democratic participation when promoting its COVID-19 contact tracing app, TraceTogether, but due to fears about digital surveillance and the concentration of personal data in the hands of the authorities, some citizens refuse to use it.<sup>15</sup>

### From 'doing-it-ourselves' to 'doing-it-together'?

What do we learn from these experiences? Although East-Asian governments may well have fared better than their Western counterparts, we must not overlook the role of residents and local communities in handling the present crisis. In some cases, citizens more readily anticipated the pandemic and its problems and acted more decisively than officials and health experts. As confirmed by previous research, when official emergency policy falls short, citizens do not hesitate to take matters into their own hands, even in ostensibly 'collectivist cultures' which are said to value social stability over individual rights.<sup>16</sup>

These observations underscore the importance for policy makers of heeding civic action and engaging with citizens early on, rather than viewing informal civic responses and relationships as governance problems that must be dealt with.<sup>17</sup> Crises and disasters are rarely resolved through top-down government intervention alone. What is needed instead is coordinated action that is inclusive of citizens and civil society groups. This is probably true for any context (Eastern, Western, democratic, autocratic), as crises become ever more complex and are increasingly difficult to manage.<sup>18</sup>

In the fight against the pandemic, civic initiatives continue to emerge across the globe: in Asia, Africa, the USA, UK, and also in my native country of Belgium, where community-based groups, such as CoronaDenktank (an informal citizen-led Corona think-tank) and CommunicatiePro's tegen #COVID19BE (which collects suggestions from citizens to combat COVID-19 and shares 'messages of solidarity' with the public), are pooling ideas and resources. We can expect more of these grassroots civic initiatives in the future, particularly – but not exclusively – citizen science initiatives that use digital tools to crowdsource data in response to urgent questions. Where and how is a hazard (biological, chemical, physical, moral) spreading? Who is infected? How are people protecting themselves? Where is help needed? Who is most vulnerable? Although the techniques used by citizen scientists may fall outside the usual best practices for validating these types of data, they can be 'just good enough' to point out knowledge gaps and to bring about policy action where and when it is most needed.<sup>19</sup>

With these considerations in mind, it is imperative that we pay closer, sustained attention to what is happening inside countries and among communities, and to how citizen scientists are beginning to collaborate across nations and regions. These foci should give us a better understanding of where, when, and how local groups can make a difference and how they can work with formal institutions, combining resources to facilitate a more robust crisis governance. Although it risks becoming a hollow, tired slogan, we must remind ourselves that crises are opportunities to do better. Many would agree that the present pandemic creates momentum to open a fresh discussion on how to do science in a more democratic and pluralistic way.<sup>20</sup> Conscientious scientists, government officials, and engaged citizens should seize this opportunity, recognizing that the magnitude, scale, and consequences of COVID-19 have bred a mutual dependence and, in some cases, closer co-operation among citizens, researchers and policy makers, with people clearly eager to help where possible.<sup>21</sup>

However, the crisis has also spurred bottom-up 'do-it-ourselves' citizen science because governments acted too late or negligently, or because citizens mistrust the state and its intentions. Clearly, without mutual trust and broad participation, government strategies to combat COVID-19 and other crises will not work. It is crucial that digital practices, tools, and data are backed by democratic safeguards to build and sustain social trust.<sup>22</sup>

These guarantees must be hardwired into crisis governance on every dimension and at every scale – and citizen science must always include community concerns if it is to remain properly democratic and become resilient in the long run.<sup>23</sup> Those who want to see durable change for the better need to act now by developing practices and strategies with citizen groups before the next crisis occurs, and by building robust alliances that allow for adaptive, flexible responses in the face of present and future uncertainties.

Members of formal institutions could begin by heeding civic demands to open scientific research and policy to the wider public, particularly as appeals to openness and public participation are often only rhetorically applied.<sup>24</sup> Rather than withhold important information, they could share it more readily and improve citizens' access to official data in emergency and non-emergency situations. This would help to combat rumours about government cover-ups and facilitate data comparison and validation across different data sources.

To better prepare for coming emergencies, policy makers and experts could initiate regular exchanges with citizen science groups, and organise joint events such as fact-finding missions and data hackathons. Such exchanges would not only bolster the 'on the ground' activities of local communities, but also signal recognition of citizen scientists as credible crisis responders who understand community needs and are able to translate such needs quickly and effectively into action. These measures would nurture a more open and inclusive crisis-governance culture, with those who are affected by a decision more fully engaged in developing research and policy questions and identifying, generating, and analysing technical information that will be used to inform actions or policies. The overriding ambition, then, should be to build institutional capacity for ongoing exchanges between diverse technical systems, stakes, and communities.<sup>25</sup>

Grassroots citizen science is not a panacea for crisis management, and there is much uncertainty about its acclaimed scientific and democratic potential. However, intractable problems such as COVID-19 require both formal and informal responses. As I have sought to illustrate, citizen science can provide resources for citizens or communities to manage urgent problems that existing institutions (e.g., government agencies, scientific institutions, oversight bodies) are unwilling or unable to manage on their own, typically because data is scarce or not openly accessible. Citizen science will not provide all the answers to present and future challenges, but it is a vibrant and potentially generative practice that formal institutions would do well to take seriously.

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Acknowledgements: I am grateful to Jennifer Gabrys, Sachit Mahajan, Sam Ward, Katie Cohen and Rob Doubleday for their helpful comments on previous versions of this essay. This work was supported by the European Commission Horizon 2020 MSCA-IF-2018 funding scheme (grant number 836989).

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### Citizen science for the food system

Christian Reynolds, Libby Oakden, Sarah West, Rachel Pateman, Chris Elliott, Beth Armstrong, Rebecca Gillespie and Michelle Patel

The food system is hugely complex, encompassing many different actors, geographic areas and cultural contexts. Although the citizen science literature related to food and food systems is concentrated primarily on a few key areas of this complex system (i.e. on health and food production); citizen science has the potential to help address many grand challenges related to food and agriculture.

In this chapter we make use of multiple desk-based reviews of the literature, and draw on our own experiences of citizen science projects. We provide examples of existing citizen science projects in the UK (as well as global initiatives) that can be adapted for use to help address food policy areas of research interest. We conclude that making use of citizen science approaches in food policy reseaarch can help the transition toward a more equitable and sustainable food and agriculture system.

### Why citizen science is particularly relevant to food and food policy

Food is a universal connection between people. What and how we eat, farm, cook, and produce affects us on individual, community and societal levels. Supplying safe, secure, affordable, sustainable, and nutritious food is a major challenge to all the different parts of a local and global system. Food is also ubiquitous and mundane, with many day-to-day food practices carried out as an unconscious routine. It is also deeply cultural and historic, involving a range of values, anxieties, and personal motivations. This universality and ubiquity make food – and the many aspects of the food system – an ideal range of topics with which to engage individuals and communities.

By the same token, multiple government actors are involved in making and implementing policy related to food. For example, in England, at the level of national government, policy affecting the food system is made by at least 16 departments and public bodies.<sup>1</sup> This number of policy actors means that citizens' voices can be absent from the public policy debate, because they do not have the mechanisms or knowledge to engage with this multiplicity of actors. Those who do engage may come from specific segments of society that have time and resources to participate (e.g. typically whiter, older and wealthier than the general population). The result of this (and other structural issues) is that specific interest groups have become the main voices engaging with government in the formation of policy, giving rise to possible policy biases towards those groups which have the capacity to engage. Research has shown that individuals who engage with citizen science projects tend to be those who are already interested in their focal topics.<sup>2</sup> However, by the same token, the pool of potential participants for citizen science can be much wider if they are engaged on the topics which are meaningful to them, using the right engagement methods.

Due to the universality of food, it is a topic that offers a wide appeal, with natural pathways to strong citizen engagement throughout the food system and policy process – after all, everyone eats. This wide appeal means that there are many opportunities to harness citizen science methods to assist with the development of better food policy and a better food system.

# Case study: Perceptions of food- comparing citizen science to other methods

Citizen science, like many other research methods, can have data biases resulting from only a subset of the population participating; and data biases could lead to biases in policy response. Because of the aforementioned issues of representativeness and engagement, we thought it essential to compare the results of similar tasks carried out either by a citizen science 'crowd', or by more traditionally recruited online survey panels (representative of the UK population), or by those recruited through social media channels.<sup>3</sup> We had each group classify images of foods according to the individual's perceptions of energy content, carbon footprint, animal welfare, and food risk. Our studies showed that different recruitment tools resulted in differences in observed perceptions on the individual level – but that overall, similar trends were observed throughout.

We highlight that the citizen science method also yielded useful qualitative engagement from participants on how to improve the research, and clarification on why some of the results were occurring. This richness of information was not available through the other methods, and was a specific benefit of citizen science engagement.

This series of projects shows that citizen science can be used as part of a wider tool box of data collection options – all of which need to be used to provide representation and quality assurance. The level of engagement with the citizen community can be a particular additional benefit of citizen science.

#### Benefits of citizen science methods for food policy makers

Scientific drivers for using citizen science approaches often relate to collecting or processing data that would not be possible to collect or process if professional scientists were working alone. By working with volunteers, large volumes of data can be processed; data can be collected across wide geographic areas and in fine detail; and/or data can be collected at high frequencies or for long periods of time. Data can also be collected from areas that are otherwise difficult for professional scientists to access, such as within the home or on private land. The everyday nature of food means that studying certain behaviours and practices can be difficult, particularly in household settings (with self-reported practices different from observed practices or direct measurement). Citizen science methods can act as a bridge to co-collect a wider range of robust information on household behaviours, and help to understand priorities for people based on their lived experience (e.g. around allergies, cooking, etc.).<sup>4</sup> Other examples of robust data collected through citizen science methods include engaging with members of the public to assess food fraud<sup>5</sup> or food safety,<sup>6</sup> quantifying household food waste, or stimulating local food production and consumption.7

Citizen science is also useful beyond the home, as citizens interact with all the multiple stages of the food system (e.g. retail, hospitality, consumption, disposal). In addition to the general public, farmers and food industry workers are also potential participants to be engaged. In farming and food production, citizen science approaches have been used to develop new practices, and to engage communities to propagate change and manage the use of anti-microbials.<sup>8</sup> Likewise, retail outlets and canteens have hosted food-related citizen science projects; citizen science approaches have been used to survey the healthiness of local retail food environments, and to empower citizens.<sup>9</sup> The current EU project SU-EATABLE LIFE, for example, focuses on mass catering in Italy and the UK, planning to reach 50,000 people and to actively engage around 5,000 citizen scientists, with the aim of propagating behaviour change to reduce GHG emissions and water use.<sup>10</sup>

Citizen science approaches can also be deployed quickly in response to sudden events or emerging issues (as has been demonstrated recently with applications in tracking and understanding the COVID-19 pandemic).<sup>11</sup> For example, one of our surveys (by Armstrong and Reynolds) was able to be deployed rapidly in the first weeks of the 2020 UK lockdown, measuring citizen perceptions of images of food. This was then extended to include how country-of-origin and ethical information altered consumer perceptions of food in a post-COVID-19 food system. These findings were then rapidly presented to policy makers and parliament to inform ongoing policy development.<sup>12</sup>

Policy makers use citizen science data in all stages of the policy cycle (problem definition, policy formation, policy implementation, compliance assurance and policy evaluation) – the collection of large amounts of data over broad spatio-temporal scales means that policy makers can utilise this evidence base for multiple purposes. Citizen science projects have also been specifically designed to address policy data gaps;<sup>13</sup> for example, such approaches are increasingly being discussed as a way to fill data gaps in Sustainable Development Goal reporting. A recent food-policy example is the FSA's 2021 joint funding call with UK Research and Innovation, 'Citizen science for food standards challenges', funding pilot citizen science projects to investigate themes in the FSA's areas of research interest.<sup>14</sup>

In addition to these national- or international-scale efforts, smaller-scale citizen science projects can also engage volunteers in generating an indepth understanding of an issue at a local scale. Such projects provide the opportunity to incorporate local, often place-based, knowledge into the scientific process.<sup>15</sup> Local knowledge is particularly important for ensuring science is relevant to people's lives and can lead to local action, in contrast with 'normal science' that aims to create findings with a high degree of validity and reliability in very specific contexts only, which may not be applicable in the real world. Findings from citizen science projects can be used to support decision making and action at a local level. The benefits do not all flow to the research itself; citizen science projects should also aim to benefit volunteer participants.<sup>16</sup> Well designed projects have shown increases in participants' knowledge, skills and scientific understanding – examples include projects that created crowdsourced open databases of potentially unhealthy food products; a foodborne illness reporting platform linked to social media; and improved yeast strains for sourdough bread.<sup>17</sup>

Individuals gaining knowledge, skills and scientific literacy in this way can lead to a number of second-order outcomes, including greater employability, behavioural changes and advocacy. Benefits to individuals can include people spending time outdoors and with other people, improving their health and sense of place, and supporting new relationship development; for example, the My Harvest citizen science project found multiple wellbeing benefits from allotment gardening.<sup>18</sup> Community benefits can include supporting stable communities with the potential for social learning, whereby people learn from each other via observation and imitation.

A multitude of benefits also arise from bringing together scientists and members of the public within citizen science projects – including increased understanding of the relevance of science (and increased trust in it), as well as challenges to traditional expert-citizen hierarchies, not least opening scientists' eyes to novel questions and considerations. Bringing diverse voices into the scientific process and having diversity in expert knowledge is a desirable goal, especially given the complexity of many of the environmental challenges we currently face. Innovation, invention and creativity are more likely to occur where people of diverse backgrounds are brought together.

Finally, however, it should also be noted that while the benefits of citizen science described above are widely discussed, the strength of evidence for many of these is weak, and not always directly related to food.

### Challenges of citizen science methods for food policy makers

As well as benefits, there are challenges with using citizen science approaches. As with any scientific endeavour, data quality assurance processes need to be carefully considered; and while aforementioned projects have demonstrated that citizen-collected data can be of the same quality as that collected by professional scientists, others have reported problems with data quality. Concerns about data quality in citizen science projects are still a major barrier to use.<sup>19</sup>

Another challenge is that citizen science participants are typically not representative of wider society. Consideration should be given to how projects (and recruitment strategies) may be designed so as to widen participation. How the demographics and characteristics of participants affect data collected – and the conclusions that can be drawn – also needs to be assessed.

Some additional legal and ethical considerations (for humans and the environment) are needed for citizen science compared with other research activities. According to ECSA's characteristics of citizen science, to be considered citizen science, participant involvement should be consensual and fully understood, and so project aims should be clearly and openly communicated with participants and other stakeholders. All those involved should be aware of, and adhere to, agreed ethical and research quality standards. Co-design of these standards between scientists and participants could be considered, in order to establish shared expectations and foster inclusion.

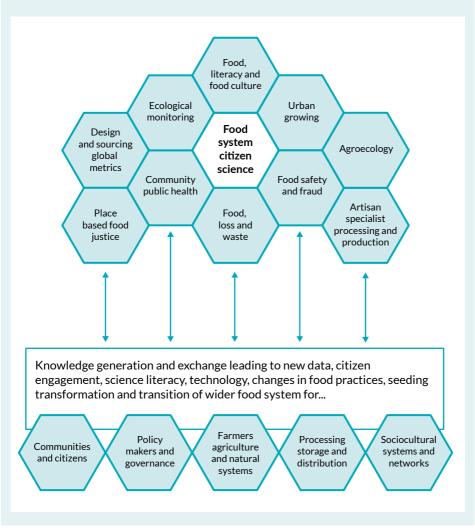
Additional ethical and legal considerations may also arise in citizen science projects in respect of data management, because of the collaborative way in which data is generated. These include issues around data ownership, data sharing, confidentiality and participant privacy (particularly when participants are also the subjects of the research), as well as copyright and intellectual property. Other issues include appropriate recognition of participants in outputs from research, and whether compensation for participation is required.

Indeed, citizen science is not always the 'cheap option' it is sometimes seen to be. Recruiting and retaining participants in projects is essential for their success, but can be costly and time consuming.<sup>20</sup> In order to keep participants engaged and contributing to projects, they need to be given feedback and encouragement, and this can be resource intensive. There may also be costs associated with processing or analysing data or buying equipment. Securing funding for projects, particularly in the long term, can be very challenging, but often the value of citizen science for monitoring particular issues, or creating change in participants and communities, only comes from long-term engagement. In studies focused on healthy corner stores in New Jersey, participants were given nominal payments of US\$25 (for a guided walk around of their food environment) plus US\$25 (for attending a community meeting).<sup>21</sup> We highlight that the issue of remuneration is contentious, with remuneration in some instances influencing participation and the quality of data collected.<sup>22</sup>

Finally, citizen science is not suited to all research questions, and consideration should always be given to whether other approaches are more appropriate.

### Mapping citizen science to food system challenges

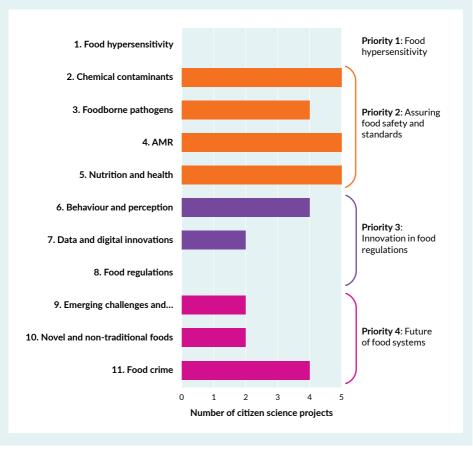
It has long been claimed that citizen science has the potential to help address many grand challenges related to food and agriculture.<sup>23</sup> We have recently categorised current and past citizen science projects as they relate to ten food domains (Figure 1):



# Figure 1: Summary of citizen science engagement with the food system and impact pathways<sup>24</sup>

We have also undertaken a parallel mapping of the FSA Research Themes to potential citizen science research projects. We found examples of existing citizen science projects in the UK (as well as global initiatives) in a range of priority policy areas (Figure 2), with many ready to be deployed now. However, our review also found some gaps (food hypersensitivity, and implementing food regulation) where there were no food specific-studies found.

## Figure 2: number of existing citizen science projects that relate to the Food Standards Agency's Areas of Research interest<sup>25</sup>



Finally, we have scoped opportunities for using citizen science to answer 26 priority research questions related to food loss and waste,<sup>26</sup> providing practical examples of how each question could be approached using citizen science methods, and the policy and commercial relevance of the information that may be produced.

These studies illustrate that citizen science methods are highly applicable to food systems issues, and adapted to a wide range of policy maker needs; and that there is a growing community of practice, with many projects ready to be deployed if funding is available. As such, it is clear that policy makers do not have to reinvent the citizen science wheel to successfully adopt citizen science methods into their methodological toolkits.

### Conclusions

In conclusion, citizen science can help with food policy development and delivery, including:

- Monitoring and quantifying issues
- Building understanding of issues
- Educating and communicating
- Leading to action by the individual (encouraging deep learning, agency), and by decision makers (drawing on evidence collected through citizen science).

Many different citizens, actors and communities can be involved: producers, processors, distributors, retailers and households/consumers.

Many policy actors are indeed already involved in citizen science projects around food, with food policy issues already being explored using citizen science methods. However, there is much room for expansion of methods, project scope, and number and type of citizens engaged. Adopting citizenscience-generated evidence as part of a policy maker's methodological toolkit could be transformative to the policy making process, to the policy makers themselves and to the communities they serve. The literature reviewed in this paper highlights that the use of citizen science benefits the research community, citizens of diverse socioeconomic and cultural backgrounds, policy makers and wider society.

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### Citizens' assemblies as a form of citizen science: A case study from Cambridge

### **Philipp Verpoort**

A citizens' assembly brings together a group of randomly selected individuals to find answers to a specific policy problem, by considering policy options and developing recommendations in the light of deliberation and scientific evidence. This places citizens themselves in the role of scientists, as they are tasked to understand and interpret scientific evidence presented to them and to use their developed understanding in making decisions. This form of involving citizens in evidence-informed policy making has recently sparked much interest in the UK, where assemblies are now being conducted on a variety of topics. This essay offers a brief account of how citizens' assemblies can be regarded as a form of citizen science, and considers one specific example, the Greater Cambridge Citizens' Assembly on traffic congestion.

### **Citizens' Assemblies**

Recent years have seen an upsurge in the number of citizens' assemblies (CAs) conducted in the UK on a local,<sup>1</sup> regional,<sup>2</sup> and national<sup>3</sup> level, on topics as varied as alcohol pricing, adult social care, city planning, or climate mitigation. Their use in the UK is inspired by impressive examples from around the world, including CAs on abortion laws in Ireland, democratic reform in Canada, and the construction of a nuclear waste dump in South Australia, to name but three. CAs (or 'deliberative minipublics', to use the technical term) are not entirely new; they were in fact invented and first explored in the 1970s.<sup>4</sup> However, policy makers are now turning more often towards these exercises in so-called 'deliberative

democracy', not least because they promise an escape route from deadlocked debates on controversial policy issues.

In a CA, a representative cross-section of society (usually between 30 and 300 individuals, depending on the scope and context) comes together over the course of several weekends in order to explore policy options addressing a specific policy problem. The participants undergo a rigorous process, whose design is (despite great levels of flexibility and continued exploration) well tested and established, and consists essentially of three phases: a learning phase, a deliberation phase, and a decision-making phase.

In the first phase, participants receive background information relevant to the problem under study, and interrogate trained (mostly scientific) experts and stakeholders. This is followed by the deliberation phase, in which participants engage in a respectful dialogue with each other, exchanging their thoughts, ideas, and arguments. In the final decision-making phase, the thoughts and preferences of individuals are converted into conclusions. The latter often includes some form of voting, but also involves compiling the agreements and disagreements of the CA members into a document which will be published as part of a public report.

### **Citizens thinking as scientists**

Very often, the topics considered in CAs combine great scientific complexity with high levels of political or societal controversy – climate change, artificial intelligence, and COVID-19 are just a few examples. The complexity of these issues often goes beyond the level of understanding that an average member of the public can be expected to possess. These problems are also typically difficult to address in open public debates, where it is hard to maintain constructive exchanges, and there is a tendency to descend into an exchange of soundbites (failing to do justice to difficult trade-offs and nuances) or oversimplified solutions (underestimating the complexity of the policy problem in question). Lately, false information – in some cases even deliberately introduced to manipulate a debate – has added an even more toxic element to our public discourse. CAs offer a way of overcoming these difficulties, by providing individuals with the required access to time, information, and resources needed to fully grasp the scientific evidence behind the issues, as well as encouraging respectful and constructive exchanges where differences of view emerge.

CAs can therefore be considered a form of citizen science, as the participants are tasked with understanding, evaluating, scrutinising, and interpreting scientific evidence in the context of policy making. It should be noted, however, that CAs differ significantly from other forms of citizen science that see citizens at the heart of the process of obtaining scientific evidence. The advantage of a CA over many other citizen science approaches lies in the representativeness and diversity of the members of the CA, which gives the process more political legitimacy and hence more relevance in the context of making public judgements. This, however, comes at the expense of the fact that individuals can only be expected to have limited capacity to engage in the process compared to other forms of citizen science. A CA usually lasts for a few weekends only, with members being paid for their participation; in contrast, conventional citizen science approaches see a self-selected group of participants commit more of their own personal time and resources, over an extended period, to the process of obtaining scientific evidence.

It is important to note that this essay sees participants of a citizens' assembly in the role of scientists despite the absence of an active search for new evidence. This is due to the scientific approach they are usually encouraged to take in order to develop recommendations for policy makers; they learn to ask questions, think analytically, and take scientific evidence into account when coming up with viable solutions or weighing up different options. This approach is similar to the one taken by trained scientists when tasked with developing advice for policy makers. It is not the obtainment of new evidence but rather the interpretation and analysis of existing evidence that is at the heart of the work done by both citizens in a CA and trained scientists advising policy.

CAs differ from conventional forms of citizen consultation in a number of ways. Policy makers normally engage with the public either by conducting surveys or by running focus groups that invite contributions from relevant

stakeholders. Surveys have the advantage of giving an estimate of the opinions of the entire population, but they can only gather these opinions on predetermined questions without giving individuals a chance to get informed about the science behind the questions they are asked or to test their views against those of others. It is also worth observing that, while surveys can pursue a similar objective to a CA – namely to determine what policy options might resonate with the wider public – surveys treat citizens as subjects of research rather than participants in the process of acquiring knowledge or making judgements. Focus groups can offer the opportunity to engage higher levels of expertise (because those who are involved can be selected for their knowledge in the relevant fields), but their views may not necessarily be representative of the wider public.

One specific example from Cambridge illustrates these differences well. In 2019, the Greater Cambridge Partnership<sup>5</sup> (GCP – a combined authority of city and county councils) tasked a CA of 60 citizens with considering policy options for reducing congestion, improving air quality, and providing better public transport in the area of Greater Cambridge. This consultation was designed to address great uncertainty in GCP's planning for the Greater Cambridge traffic system, which it had previously not been possible to resolve through the production of public surveys, stakeholder workshops, focus groups, and expert reports.

Scientific research had suggested that the expected development of the Greater Cambridge area would result in trends of growing traffic and population, and that action would be required to prevent further escalation of existing problems of congestion and air pollution. Despite an urgent call for action from expert planners – and despite the availability of detailed information on possible long-term scenarios – public support for bold measures to implement these was hard to identify. Surveys indicated general support for change, but little support for concrete policies. Focus groups saw specific interest groups make vocal demands for particular measures, but failed to show whether these would reflect the interests of the wider public.

## The Greater Cambridge Citizens' Assembly

In search of a mandate from the wider Greater Cambridge population for concrete policy options, the GCP conducted the Greater Cambridge Citizens' Assembly, a process that involved 60 randomly selected citizens<sup>6</sup> to represent the diversity of the population in terms of gender, age, ethnicity (self-identifying as white or black and minority ethnic), socioeconomic background, travel regularity, most frequently used mode of transport, and geographic location. They were tasked to consider a range of possible policies presented to them, including the introduction of a congestion charge or a pollution charge; increasing workplace parking levies; closing roads to vehicles; or pursuing no intervention at all. These were ranked by popularity among assembly participants, following many hours of intense learning and deliberation, in which assembly members had to weigh up the different options based on the advantages and disadvantages as well as risks and benefits that previous studies had predicted.

As a result, options for which public acceptance was previously hard to discern were found to enjoy high levels of support. CA members explained that they had felt that way after they had understood the need for and relevance of these measures. Intriguingly, the assembly also proposed ideas not anticipated by the GCP: a lollipop bus service (a rerouting of buses that would make the public transport network run more efficiently), as well as the idea to franchise bus services on a Mayoral level, both enjoyed great support among assembly members. The former was the result of a local community action group presenting one of its studies to the assembly, from which the assembly members drew their own conclusions and identified the suggested plan as a preferable solution. The latter was brought up by assembly members themselves, having understood the challenges arising from the fact that operating certain bus services in the city was economically infeasible. This combination of responding to top-down proposed solutions, while also coming up with bottom-up approaches, is desirable and indicates a good blend of understanding of scientific facts, creative thinking, and a target-oriented approach on the part of the participants.

The results of the Greater Cambridge Citizens' Assembly, which have since been compiled into a report<sup>7</sup> and considered in several council meetings, give a clear and strong mandate to the GCP. It is now mandated to implement bold measures and effect the change necessary to break existing trends of growing congestion and air pollution in Cambridge, while also being enabled to describe precisely what measures are preferred and supported by assembly participants.

# Conclusions

While the consequences of this report in the coming decades have yet to be determined by the GCP and the Greater Cambridge area, this case study clearly demonstrates the usefulness of CAs for policy making. Given the complexity behind city planning and the traffic system, it is critical to provide individual citizens with the time, opportunity, and resources they need in order to evaluate the scientific evidence behind competing policy options. In Cambridge, this was achieved by allowing assembly members to spend two full weekends of their time in the assembly process, incentivised by offering both remuneration and also support for those with special needs. Furthermore, expert scientists presented evidence and helped with the conveying of information to participants, while remaining independent and ensuring that the material presented was balanced and accurate. Finally, the process gave a mandate to individual citizens, which gave them a feeling of urgency in their work and prompted them to take the process very seriously. All this allowed citizens to go beyond their everyday understanding of the Cambridge transport system, and to make their judgements based on a more scientific perspective. Giving citizens an evidence-informed scientific perspective in this way has great potential to benefit similar situations in the future, wherever communities need to address policy problems and topics of equally high scientific complexity.

The Sortition Foundation – with which the author of this essay is affiliated, and which recruited the 60 participants of the Greater Cambridge Citizens' Assembly mentioned above – is committed to making CAs, deliberative mini-publics, and generally any type of body of randomly selected individuals a central part of future policy making and political decision making. The impact of this work has grown substantially over the past few years and will continue to place citizens at the heart of decision making. As argued above, the nature of the process will also allow citizens to adopt a much more scientific perspective in the context of policy making, which can be considered a form of citizen science.

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## **Endnotes**

- The list of CAs in the UK is hard to keep track of, but here is a short (likely incomplete) list of City Councils, Borough Councils, or Mayoral Districts who have over the past two years (prior to writing this essay) conducted CAs on a local level on a variety of topics: Leeds, Kingston, Newham, Lancaster, Kendal, Cambridge, Brighton, Tees Valley, Adur and Worthing, Warwick, Blackpool, Test Valley, Dudley, North of Tyne, Lambeth, Devon, Thames Valley.
- The Scottish and Welsh parliaments as well as the Northern Irish National Assembly have all experimented with CAs in their policy-making work.
- The UK parliament conducted two CAs in the past two years: a CA on Adult Social Care and Climate Assembly UK.

- 4. Ned Crosby invented the 'Citizens' Jury' in the US in 1971, while Peter Dienel started a similar process called the 'planning cell' in Germany.
- 5. See the website for further details: www. greatercambridge.org.uk.
- 6. Of the 60 selected, 53 participants continued until the final CA session.
- The full report was published on 20 November 2019 and can be found on the website of the Involve Foundation: www.involve.org.uk/ resources/blog/project-update/final-reportgreater-cambridge-citizens-assembly-published.

# Using citizen science to respond to the policy challenges of the COVID-19 pandemic: A case study from healthcare improvement research

# **Ruth Kern**

The Healthcare Improvement Studies Institute (THIS Institute) – a partnership between the University of Cambridge and leading charity the Health Foundation – was established in 2018. Its aim is to strengthen the evidence base about how to improve the quality and safety of healthcare in the UK. The Institute is home to a multidisciplinary team of researchers using innovative methodologies to develop and extend the field; and the use of citizen science to deliver large-scale research projects was designed into THIS Institute's plans from the very beginning.<sup>1</sup>

Fundamental to THIS Institute's values are collaboration and inclusivity. We believe that engagement, involvement and collaboration with the diverse stakeholders in the UK's health systems – including, crucially, the participation of patients themselves – are essential for creating better evidence, and thereby improving quality and safety in healthcare. By using citizen science approaches, in particular online methods, we seek to increase the scale, broaden the geographical reach, and improve the accessibility of research and development. We also aim to offer new ways of carrying out research that combine scientific rigour with ways of engaging participant experiences. Using two case studies from THIS Institute's rapid-response research during the COVID-19 pandemic, this essay reflects on how using citizen science in research might help develop and implement policy. We start by briefly explaining the background to our approach.

## **Citizen science at THIS Institute**

In our work, we seek to move towards the goals of citizen science by:

- Engaging with larger and more diverse groups of participants than traditional research
- Involving participants in research tasks rather than simply as contributing data points
- Creating, designing and developing research programmes with and for participants
- Recognising and acknowledging the contributions of participants in the research.

A distinctive feature of our research is that it often specifically seeks the personal expertise that participants bring to the project – for example as a patient or staff member – and engages the knowledge, skills, creativity, and lived experience of those who use, provide or organise healthcare. Taken as a whole, our programme of work meets all the European Citizen Science Association (ECSA)'s ten principles of citizen science in supporting participation, engagement, involvement and collaboration. (Note, however, that there has been active debate since the founding of THIS Institute about the use of the term 'citizen science' to describe our approach. In part to cut through the range of different understandings, we tend to refer to 'participants' or 'experts' – by which we often mean experts by experience, not just by professional training.)

THIS Institute has developed an online R&D platform, Thiscovery (www. thiscovery.org), to support large-scale health services research. Thiscovery hosts a range of online tasks, including surveys; video interviewing; asynchronous interviewing (enabling participants to video- or audio-record their responses to written or video prompts); and Delphi-style consensus-building processes. New functionality is being added all the time, including discrete choice experiments and photo upload and tagging.

From the users' perspective, Thiscovery seeks to create attractive and engaging experiences for participants, including through gamification techniques. From the researchers' perspective, the platform can reduce the administration overhead by reducing time to set up, facilitating participant information and consent, booking appointments, managing data securely, and increasing the speed of data collection; it can also help reduce costs (particularly travel costs).

While Thiscovery is not our only approach to engaging with large groups of participants (nor indeed can it be, given that online technologies are not yet accessible to all), nevertheless it was crucial in enabling THIS Institute's research programme to transfer online at the start of the COVID-19 pandemic in March 2020. Despite the fact that face-to-face contact with research participants became almost impossible (particularly in healthcare settings) at that point, the arrival of the pandemic led to a year of rapid growth. Between March 2020 and February 2021 we reached over 2000 participants through Thiscovery, and completed data gathering for eleven research projects, with a further four projects in the pipeline.

# Case study 1: Bringing together diverse expertise to problem-solve at speed

In response to the COVID-19 pandemic, THIS Institute rapidly reoriented its research programme towards developing evidence-based responses to the real-life and urgent challenges facing staff and patients in the NHS. One example of this is the 'consensus building on obstetric emergencies' project which began in April 2020, just after the start of the first lockdown in the UK. The imperative for the project lay in the need, at the start of the pandemic, to adapt established healthcare processes in order to manage the risk of infection. But making process improvements locally can mean a lot of re-inventing the wheel, and variation across organisations; and local organisations may not always have access to rare expertise. The solution is likely to lie in large-scale collaboration – the very thing that the pandemic was making so difficult to achieve.

This particular project addressed the need to adapt the management of an obstetric emergency (such as post-partum haemorrhage) to a COVID scenario. To support the NHS, THIS Institute developed a large-scale collaborative approach aimed at sourcing expertise that was not always available at a local level, reducing duplication of effort, supporting shared understanding, and enhancing ownership of the solution by involving in the design the staff who would be using it.

To stimulate participants to think about what an ideal process would look like, a video was created to illustrate one possible way of managing obstetric emergencies in women with suspected or confirmed COVID-19. Using Thiscovery to host the video and collect feedback, we engaged over 100 specialists (recruited through the Institute's networks) working in maternity care, infection prevention and control, and human factors. After watching the video, participants provided over 900 recommendations on how to improve the practice illustrated. Content analysis identified the 22 most frequent recommendations. Participants were then invited to score them according to how important they felt that it was for each recommendation to be implemented. In the first round of scoring. consensus was reached on 12 recommendations. In a second and final round, participants were asked to review recommendations where agreement was not yet clear, and to consider their scores again in light of the scores from other participants. As a result, agreement was reached on 16 recommendations. The original video was updated to incorporate these 16 recommendations, and an infographic and a short summary of the key points was produced. All of these outputs can be found on THIS Institute's website<sup>3</sup>

In this project, Thiscovery enabled a pace and scale of work that would otherwise not have been possible. Its reach has been extensive. The final video was endorsed by the PROMPT Maternity Foundation, the Royal College of Obstetricians and Gynaecologists, the Royal College of Midwives, the Obstetric Anaesthetists Association, Each Baby Counts, and the Infection Prevention Society. It has been viewed over 15,000 times, and has been retweeted by, amongst others, the Chief Midwife Jacqueline Dunkley-Bent, and patient safety advocate Martin Bromiley. The first academic paper from the work, which has recently been published<sup>4</sup> by the BMC Medical Research Methodology journal, recognises the work of the study participants through a contributor group.

# Case study 2: Inclusive research to create enduring learning for future improvement

During the COVID-19 crisis in the UK and elsewhere, the number of people in need of mental healthcare has increased. Lockdowns and other interventions to reduce transmission increased social isolation, loneliness and domestic strains, creating adverse conditions for mental health. Yet, as need increased, the capacity of mental healthcare provision was severely restricted due to distancing measures, extra hygiene precautions, abrupt changes to care pathways, and reduced staff availability. In response, many services switched to various forms of remote care as a way of increasing capacity and reducing face-to-face contact. These included the use of telephone and online methods of providing care.

In summer 2020, THIS Institute launched a study aimed at capturing a wide range of experiences of accessing and providing secondary mental health services during the pandemic, in order to inform principles for good practice in maintaining access to these services. Participants were involved in designing the research, and 65 interviews were carried out with people

who had either accessed or needed to access English secondary mental healthcare during the pandemic, as well as carers of people with mental health difficulties, and staff working in NHS secondary mental health services.

Significant efforts were made to ensure participation from diverse backgrounds (including those from minority ethnic groups, who were more severely affected by COVID-19):

- **Engagement**: the study was designed and developed with people with lived experience of the issues, including service users, carers, and a peer researcher from a mental health research charity.
- **Recruitment**: the recruitment strategy was aimed at maximising diversity of views, with participants recruited through the networks of the Institute, mental health charities such as Rethink Mental Illness, National Institute for Health Research (NIHR) Applied Research Collaborations, and specialty clinical networks.
- **Inclusion**: the researchers were mindful of digital exclusion, and while the majority of the study was delivered via Thiscovery, the team also offered telephone participation to support those without access to the internet.

The findings from the interviews and subsequent consultations with members of the three stakeholder groups indicated that remote mental healthcare was a topic regarded as particularly important and worthy of investigation. The initial results of the study, published in BMJ Open,<sup>5</sup> showed that experiences of remote care in all groups (service users, carers and staff) were mixed. Particular concern was expressed about the poor fit between some mental healthcare needs and remote forms of provision, and about the risks that remote care might exacerbate inequalities. The next phase of the work will aim to describe 'what good looks like' in relation to remote mental healthcare, by building consensus among mental health service users, carers and staff.

## Learning for policy makers

**Diversity is central to good citizen science**. Capturing a diverse range of experiences, perspectives and expertise is not easy; but it is an important ethical obligation, and it is essential for conducting high-quality citizen science research that can lead to good policy and support implementation. Working via an online platform can improve the diversity of participants involved, as it provides an opportunity to participate from anywhere at any time. This is particularly important for shift workers and people with other employment and caring responsibilities that might prevent them from participating during traditional nine-to-five working hours. Offering a range of opportunities for participation – e.g. from very small tasks like answering a short questionnaire, up to multi-stage processes like consensus building – can also increase inclusion.

It is important to acknowledge, however, that online participation can exclude other groups, those who may not have access to wifi or internetenabled devices, or who may not be comfortable or able to participate in research online. In many projects, therefore, we offer support for those who can get online but need help to understand and participate in the online tasks; we also offer alternative remote routes (for example telephone or postal surveys) for those unable to get online. In the case of the mental health project, we wanted to ensure that we could reach participants from particular backgrounds so that their views could be represented, as health outcomes can vary significantly with ethnicity, socio-economic background, and other demographic factors. We worked with our networks and built relationships with new trusted intermediaries in order to record and include those views.

A strong base in scientific method is important for transparency, trust, implementation, and impact. Using established scientific methodologies and transparent processes helps policy makers and other stakeholders to make judgements on the results of citizen science research. For example, using a Delphi-style consensus-building methodology to identify the recommended changes in the obstetric emergency video was key to the emergence of consensus; the scientific credentials of the methods used also ensured that the proposed changes enjoyed credibility. This approach can provide a firm base for coalition building around a particular change, as shown in this case by the wide range of endorsement secured for the new video guidance, and can thus support implementation and a pathway to impact.

Online approaches enable timely contributions to policy development and encourage participation. Using online approaches during the pandemic has allowed THIS Institute, and the policy stakeholders we work with, to rapidly deliver citizen science in way that is timely for both healthcare practice and policy. For example, there is huge policy interest in learning what changes in care should endure post-pandemic, particularly in the role of remote care provision. The ability to set up work rapidly means that we can take advantage of the real-time experiment in remote care provision, to support policy makers in their decisions about what care might look like after the pandemic; by drawing on the experiences of expert participants in real time, we hope to learn which aspects of remote care might be retained, and which elements might be better delivered face-to-face in future.

Delivering this kind of relevant and timely research relies on the generosity of expert participants with their time – but by the same token it is the relevance and timeliness of the work which encourages participation. Being able to mobilise quickly creates a virtuous circle of participation and relevance. We further show our respect by acknowledging contributions through forms of authorship where appropriate.

Online approaches to citizen science enable nationwide expertise to contribute to local policy making. During the pandemic, local health systems or even individual hospitals have had to transform policies and procedures at fast pace and often without access to an evidence base. Using Thiscovery, THIS Institute has been able to demonstrate that online citizen science can rapidly gather, analyse and synthesise knowledge and experience from a wide range of geographies, specialties, professions and lived experiences, supporting local policy makers to build the evidence rapidly.

#### **Developments for the future**

These case studies are relatively small in scale, and as yet can only offer indications of how citizen science could support and influence policy making in the future. There is much more to be done both to explore the full potential of citizen science, and to establish the evidence base for its efficacy. Some future developments are suggested here.

**Increasing the scale of citizen science approaches**. To widen participation in the future, we aim to create enduring citizen science communities in healthcare improvement research. This will give researchers rapid access to expertise, and also establish a known and trusted forum in which expert participants can share their knowledge. The creation of communities and the increased scale of citizen science approaches will also support communication between research teams and other participants; in time, research programmes may also be designed and led by citizen scientists.

**Continuous improvement in accessibility and user experience.** We have already found that different groups of participants may react very differently to the same citizen science tasks. An example of this is the facility that we provide for participants to record video responses to question prompts instead of participating in real-time video interviews (we call this 'asynchronous' interviewing). Some participants really appreciate this form of participation, finding it easy and intuitive; others find it challenging and somewhat off-putting. An ongoing challenge for research teams and citizen scientists working together will be to offer a range of accessible processes both online and offline that facilitate the involvement of everyone who might want to participate.

**Developing the methodological and theoretical basis for citizen science**. To support policy makers and other stakeholders in assessing the value of citizen science in healthcare improvement, it will be vital to continue to develop it as a science. This will involve methodological innovation, theoretical development, and building capacity in research teams.

### Conclusion

Online approaches have great potential for expanding the number and diversity of citizens who can contribute to health services research. Using scientific methodologies to make the most of their expertise offers the prospect of a step change in the quality of evidence available for policy makers to use in developing improvements in healthcare. At the same time, the process of involving citizens – particularly those with a significant stake in the system, such as healthcare workers – in research and policy development should in turn lead to improved take-up and implementation.

Although there is more to do in increasing the accessibility of online approaches and establishing the field of online research methodologies, we hope that the experiences outlined above give cause for optimism about what can be achieved.

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# 3. PUBLICS, PARTICIPATION AND GOVERNANCE

**Citizen infrastructures and public policy: Activating the democratic potential of infrastructures** Jennifer Gabrys

Data governance for the 21st century: Citizen dialogue and the development of data trusts Jessica Montgomery and Neil Lawrence

Why is it so difficult to integrate citizen science into practice? Muki Haklay

# Citizen infrastructures and public policy: Activating the democratic potential of infrastructures

# Jennifer Gabrys

Citizen science – and many related forms of public engagement – are now informing policy across local and national government around the world. However, citizen science can often be relegated to a mere data-gathering exercise, where publics input evidence, opinions, and observations that may or may not be incorporated into policy making. In this essay I consider how citizen science can go further, and contribute to projects for building citizen infrastructures that both generate and sustain democratic exchanges.

Citizen infrastructures are arguably one of the key and under-recognised components of citizen science. Whether they take the form of digital platforms, community forums, shared skills, information networks, or lived environments, there are a number of spaces and exchanges that build capacity and contribute to the conditions that support and enable participation. These infrastructures have the potential to ensure more sustainable and democratic modes of public engagement that can be both citizen-led and more enduring. But what are these infrastructures?

# Infrastructures of, by and for citizens

Infrastructures are often at the heart of discussions on the green recovery. Infrastructure building projects are claimed to address economic decline, rebuild social life, redress inequality, and prevent environmental collapse. Housing, energy, transport, telecommunications and other 'major' infrastructure projects are all presented as transformative developments that can remake unsustainable living patterns. This is a tall order for any infrastructural project, green or otherwise. There is, however, generally very little discussion about how such infrastructural projects are identified as the most viable or transformative. These projects are typically presented as decisions best taken by governments and companies, with comparatively little public input. At the same time, many countries are now spending more money on 'brown' than 'green' infrastructure, thereby demonstrating how difficult it is to break out of the infrastructural status quo of fossil fuels, pollution, and environmentally damaging systems.<sup>1</sup> But moving from dirty or 'brown' to potentially sustainable or 'green' infrastructure requires more than replacing forms of energy; for infrastructure to become sustainable, it must incorporate more equitable and less extractive environmental, social, political and economic processes.

Which brings us to the question: to what extent might infrastructures form through (and as) spaces for democratic exchange – whether in the form of citizen science or other civic contributions? In other words, how might public engagements such as citizen science contribute to identifying and developing infrastructural projects, and simultaneously how might these contributions create infrastructures for ongoing exchange? Public consultation and deliberative meetings can be one way to gather input, often through designated channels and spaces separate from everyday spaces of democratic exchange. But communities are also involved in making infrastructures through their everyday practices. The lived environments within which people interact, and to which they contribute, can also inform the very possibilities for ongoing collective exchanges.

Numerous texts and projects now consider how to develop public-interest technologies, social infrastructures, infrastructures of participation and more.<sup>2</sup> The general role of infrastructure might be identified as organising resources in common, and facilitating exchanges to ensure equitable distribution across diverse people and communities. If infrastructures within the context of green recovery are to be equitable, democratic, and sustainable, then citizen science might be one way to identify, build, and test such projects and make them as transformative as they promise to be.

Infrastructure developed of, by and for citizens would then need to account for citizen contributions as an ongoing feature and emerging property of the use and construction of infrastructures. At a time when the focus of attention is most often on major physical and technical systems, it becomes even more important to keep in view how infrastructures also require and shape relations and exchanges that can make or break civic life. In some ways, this is what various social researchers refer to as 'infrastructuring', where contingent practices and exchanges shape and even create infrastructures.<sup>3</sup> Indeed, infrastructure is as much formed through people and their relations as it is through physical systems.<sup>4</sup> Moreover, infrastructures can be rendered ineffective or obsolete without ongoing citizen contributions. Citizen science, and many other forms of public engagement, can build infrastructures of participation, both as spaces of democratic exchange, and as material-technical systems generated through such exchanges.

# Citizen Sense: an experiment in building infrastructure

One example of a project that has experimented with building citizen infrastructure is Citizen Sense.<sup>5</sup> Since 2013, this participatory research project that I lead – has worked with communities in the US and UK to build, install, and test digital sensors to monitor air pollution. Sensors are key technologies within the 'smart' infrastructures of digital cities;<sup>6</sup> yet the development of these technologies and infrastructures often takes place beyond the reach of citizen input, or through participation that is more scripted than genuine. At the same time, numerous DIY and low-cost sensors are now available for citizens to monitor environments (or other applications). The Citizen Sense project has focused on the rise of these digital technologies, along with the forms of citizen participation that they would organise and activate.

In the course of this research, Citizen Sense worked with communities to monitor air quality by identifying environmental problems and emissions sources, building and installing sensors, analysing and narrating data, communicating findings to policy makers and regulators, and making proposals for how to build more liveable environments. The research process gave rise to an emerging citizen infrastructure, which we consolidated into a toolkit ('AirKit'). The toolkit seeks to enable other communities to build on the process, knowledge, resources, and digital platform that we developed through multiple participatory investigations into air quality.<sup>7</sup>



Community plans for transforming Old Tidemill Wildlife Garden, posted in response to a disputed housing development planned for the area. Deptford, London



Setting up a Dustbox for monitoring particulate matter, and discussing community planning projects for local infrastructure. Deptford, London

Photo by Citizen Sense, 2016

As a citizen-sensing infrastructure, AirKit developed through ongoing testing and use with people monitoring their own environments, before consolidating into a toolkit that could be taken up across multiple locations. In this sense, it is an infrastructure twice over: both as a citizen-science toolkit for monitoring environments, and as a mode of exchange for proposals to improve lived environments by building more sustainable and just infrastructures. Infrastructures are now commonly understood to operate in this double or even pluralistic way: as physical structures, social exchanges, and conditions for making and sustaining collective and democratic life.<sup>8</sup>

# Activating democratic infrastructures

Just as there are many ways to organize citizen science projects to inform policy, there are also many possibilities for testing and furthering the democratic potential of these forms of participation. Citizen science could contribute useful and inventive data that expands beyond expertled datasets, enabling more participatory engagements with social and environmental issues. At the same time, it could contribute to more than data gathering, by building infrastructures for public exchange – whether in the form of digital platforms, community organisations, or social forums. It could also enable democratic engagement with many of the other infrastructure projects now underway, from where to locate walking and cycling paths, through proposals for community energy, to landscape restoration initiatives which address climate change in a more systemic way.

Rather than encounter infrastructures as fixed technical-material systems imposed through top-down modes of governance, it might be possible to activate the democratic potential of infrastructure through citizen science and public engagement projects that use, make and remake these organisational forms – and so bring about a more just and sustainable social life. Such infrastructures could provide spaces for collective exchanges and co-creation, encouraging multiple, diverse and divergent contributions which can ensure the ongoing relevance and integrity of these systems.

Infrastructure to support citizen science might then consist of digital platforms and knowledge sharing, policy-maker forums and neighbourhood pilots, funding workshops and listening sessions, which together contribute to more pluralistic, just and democratic worlds. These approaches are needed now more than ever, as strategies for addressing environmental pollution and pandemics, social inequality, and planetary change.

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# Data governance for the 21st century: Citizen dialogue and the development of data trusts

# Jessica Montgomery and Neil Lawrence

As more data is created from a growing range of digitally mediated interactions, there are opportunities to use data in policy – from nowcasting metrics for economic performance, to the design of targeted public-health interventions. Many of these new forms of data are the result of happenstance; they are generated by individual citizens in the course of daily activities, without having been collected with a public policy goal in mind. While use of such data can create significant benefits, its use also brings new potential forms of harm and risks, further disenfranchising individuals in decisions about data sharing and use. In this context, there is a demand for institutions that can bridge the desire to share data for social and economic benefit, with concerns about the vulnerabilities that such data sharing can create.

Data trusts offer a framework for creating such institutions and bringing citizen voices into decisions about data use. These trusts have been the subject of widespread policy attention in recent years, but there remain important challenges to be addressed in moving discussions from theory to practice. Central to the next phase of development for data trusts will be the creation of pilot projects to experiment with ways of working and forms of citizen engagement. Data trusts will need to seek ways of aligning incentives between individuals, groups and organisations; of ensuring that they are accessible to all in society; and of engaging effectively with their members in new forms of participatory governance.

## Policy responses to a new data environment

Today's data environment is fundamentally different from that of ten years ago. A far greater volume of data is now generated from a much wider variety of sources than before. Much of this data comes about by happenstance; it is produced or collected as a result of individuals interacting with digital systems or services as part of their everyday activities at home or in the workplace. The growth of such happenstance data generation has facilitated rapid advances in data science and machinelearning technologies, which can extract insights from large amounts of data and deploy these insights to inform decision making.

Recognising the opportunities associated with this new data environment, policy makers across the world are developing data and AI strategies to promote data use. In the UK, for example, the draft National Data Strategy sets out the Government's ambitions to use data to boost economic growth, create new jobs, improve public services, advance research and benefit society.<sup>1</sup> The ability to share and use data in ways that command public confidence, based on trustworthy data governance frameworks, is the foundation of these policy agendas.

The key challenge for data policy today is to bridge the aspiration to share data for economic and social benefit with concerns about how to manage the harms that can emerge as a result of data use. Data governance is central to bridging this gap. Because happenstance data pertains to individual citizens, its governance needs to be designed with citizen needs and rights in mind, embedding social interests and concerns in mechanisms for data stewardship. Such mechanisms can make use of a variety of different data governance tools, including technical solutions or standards, organisational processes, and legislative frameworks.

Existing legislation already creates a constellation of data rights that aim to prevent harms from data sharing and to empower citizens to influence how data about them is used. Further action is now needed to support individuals in exercising these rights while promoting desirable data uses.<sup>2</sup> Technical, legal, policy and organisational interventions can each play a role in helping to achieve these objectives. Various new approaches to data stewardship are also emerging, creating opportunities to bring citizen voices into decisions about data use in innovative ways. To further develop these approaches, researchers and policy makers can take lessons from both recent experiences of data sharing for public benefit, and previous public dialogues about data and digital technologies. We consider these in turn below.

# Lessons from data policy and COVID-19

The onset of the COVID-19 pandemic put data front-and-centre in public conversations about policy, with epidemiological data and modelling outputs scrutinised by policy makers, journalists and wider society. In the hope that powerful data analytics methods could be deployed on diverse datasets to reveal new policy possibilities, this period also saw decision makers turn to happenstance data as a new source of evidence for policy making, and to data science as a new tool for policy development.<sup>3</sup>

With the pandemic affecting almost every aspect of daily life, a wide range of data sources have the potential to be used to better understand the impact of COVID-19 on society. Data from mobile phones can show changing patterns of mobility;<sup>4</sup> credit card transaction data can show patterns of consumer behaviour;<sup>5</sup> self-logging of COVID-19 symptoms can indicate patterns of community transmission.<sup>6</sup> Deploying these happenstance data resources at times of crisis requires careful co-operation between the private sector (which collects much of the relevant data), the public sector (which can provide an institutional base for governance), and academia (which can supply expertise to support analysis), as well as careful consideration of citizen concerns.<sup>7</sup>

In the UK, the DELVE Initiative was convened by the Royal Society with the aim of bringing the UK's data science and machine-learning expertise to bear on pressing COVID-19 policy questions. As DELVE developed its work – using data science to answer questions about the effectiveness of face coverings in reducing transmission, the design of test and trace systems, the impact of hospital-acquired infections in seeding community transmission, and more – access to data became a continuing challenge. Despite the desire of governments, researchers, and companies to make use of novel data resources to design effective policy interventions, a range of practical challenges repeatedly held back these efforts (Box 1).

# Box 1: Actions needed to increase the UK's data readiness for pandemic response

Despite the desire from government and the research community to use data science in policy making, DELVE encountered a range of barriers to data access and use that held back such collaborations. To better support data use in policy making, DELVE identified three key areas in which action is needed to bolster the UK's data governance foundations and enable trustworthy data use:

- Accelerate the data preparation pipeline, supporting organisations to become 'data ready' through interventions that improve data quality within organisations and build skills in data management and use.
- Build capability for long-term data sharing, through pilot projects that bring together policy makers, researchers and the private sector to use data science on key policy challenges, and that embed data science capability across Whitehall.
- Create incentives for responsible data sharing, streamlining data governance processes and encouraging organisations to make data available for use in public policy.

In the near term, DELVE called on Government to implement three key recommendations:

• Government should update the statutory remit of the Office for National Statistics (ONS), giving it the power to access 'happenstance data' from a wider range of actors in order to generate national and local statistics for use in decision making.

- The ONS should collaborate closely with the Information Commissioner's Office (ICO) to create a standard qualification for access to certain data types a sort of 'data driving licence' that would help streamline data access arrangements for qualified researchers.
- Government should invest in interdisciplinary pathfinder data projects, bringing together industry, academia and civil servants to work on cross-Whitehall projects targeting specific policy questions. These could include, for example, the use of mobility data for public policy, or new approaches to nowcasting economic measures. The idea is that each project should leave a legacy of expertise about how to make data sharing activities work across departments.

#### Source: Royal Society DELVE Initiative (2020)

DELVE was not alone in experiencing these difficulties. A recent survey by the UK Government's Centre for Data Ethics and Innovation (CDEI) suggests that advanced data analytics methods have played a relatively small role in the UK's COVID-19 response. Instead, where data science has contributed effectively to policy making, more success has been found in using conventional data analysis methods in combination with new data sharing arrangements.<sup>8</sup>

At the same time, public conversations around data use in the COVID-19 response have highlighted the wider concerns that the use of happenstance data can create. Polling during 2020, for example, suggested that many people have concerns about whether existing governance systems are sufficient to ensure that data and digital technologies are used responsibly.<sup>9</sup> Public conversations about data use have illustrated the range of tensions that can arise in data governance – between individual rights and community needs,<sup>10</sup> and between the benefits of data use and its potential to cause harm.

DELVE's work was focused on the action needed by Government to strengthen its preparedness for future crises. It highlighted the range of

actions needed to better deploy existing data resources for public benefit, from organisational data maturity assessments to standardised data access requirements. While these recommendations are important in tackling near-term data access challenges, further action is also needed to ensure that, over the longer term, patterns of data access and use are aligned with citizen interests. Achieving such alignment will require institutions that can represent citizen voices in negotiations about data use, and that can help rapidly deploy data resources in the public interest at times of crisis.

Responding to this demand, new forms of data institution are already emerging, seeking to provide 'bottom-up' ways for individuals and organisations to support desirable forms of data use.<sup>11</sup> These data intermediaries provide platforms or frameworks for data stewardship, with the aim of increasing access to data while supporting individuals in the exercise of their data rights. Developing these new institutions requires further action to connect citizen concerns about data use to the operation of these new data intermediaries.

# Public dialogues on data: understanding the contours of desirable data use

Prompted by the excitement surrounding recent advances in artificial intelligence technologies, the last five years have seen a variety of public dialogue exercises seeking to identify the contours of acceptable data use. While each has taken a different lens on data use, taken together, common themes emerge:

• Individuals perceive both benefits and risks from data use. Citizens are generally supportive of data sharing, so long as there are clear public benefits alongside safeguards to prevent misuse. Individuals can see clear benefits from better use of data,<sup>12</sup> but have concerns that data might be misused for purposes other than that for which consent was given; that organisations might not implement effective systems to manage data security or privacy; or that autonomous systems could cause physical harm to people in their environment.<sup>13</sup>

- Perceptions of trustworthiness vary. Individuals tend to report higher levels of trust in government, the NHS and universities than in commercial organisations.<sup>14</sup> The question of 'who benefits' from data use or technology development is key; where individuals can see a clear public benefit, they are more likely to be supportive.<sup>15</sup>
- There is no single public view on acceptable use of data or digital technologies. Attitudes vary across different applications of technology, across demographics and across time.<sup>16</sup> This variation highlights the importance of data governance approaches that embed engagement and dialogue in their ways of working, giving individuals and communities the ability to influence how data about them is used, and for what purpose.

In evaluating the use of data and digital technologies, individuals repeatedly return to questions about who is using their data, why, and for whose benefit. In response, data governance mechanisms are needed that can enable data use in areas where citizens wish to see benefits, but put limits on its use elsewhere.

# The institutional gap in data governance and citizen engagement

Various different frameworks to support data sharing and use already exist, making use of different legal or institutional arrangements. The term 'data institution' today describes a variety of structures – corporations, co-operatives, unions – that have been created with the aim of stewarding data use for a specific purpose.<sup>17</sup> These purposes include securing benefits for individuals or organisations, pursuing 'social good' or public policy goals, and giving communities a voice in decisions about data use.<sup>18</sup> The choice of data sharing structure reflects the values and aspirations of those involved in the data stewardship activity.

While successful in enabling many new uses of data, these existing mechanisms have struggled to adapt to the challenges of today's data environment. Reliance on consent as the basis for data sharing through contracts presupposes the time, resources and ability to negotiate conditions for data use that most do not have; current governance systems often fail to account for the relational aspects of data use, and the ways in which decisions made by one individual about 'their' data might affect others; and the power asymmetries in the digital environment today make it difficult for individuals to meaningfully opt out of data sharing, without losing the ability to participate in many common activities.

Adding to these challenges, the ability to use and re-use data in new ways is placing further strain on current data governance practices. Complex patterns of data use and re-use create the risk that sensitive insights about individuals could be created by combining datasets in new ways. They also create the conditions in which individuals' daily lives and experiences can be shaped in subtle or nefarious ways, with implications for their ability to fully express their agency in the digital world.<sup>19</sup> These forms of harm are different from those envisaged by many of today's legislative frameworks, which focus on individual instances of data use to make decisions with recognisably significant personal or social consequences. In this context, society's ability to realise the full potential of data requires more effective tools to limit how different stakeholders can use it.<sup>20</sup>

Together, the limitations of current governance approaches, and the new challenges associated with changing patterns of data use, create an environment of asymmetric power. It is increasingly difficult for individuals to influence how data about them is used, whether in promoting data use for desirable purposes or preventing undesirable use.

New data institutions are needed to fill this 'agency gap.<sup>21</sup> These institutions would seek to shift the balance of power in the digital environment, empowering individuals or groups to more effectively influence the terms of data use, either by promoting desirable uses or asserting their data rights to prevent undesirable ones.

## Data trusts: a new tool for data stewardship

In conditions of asymmetric power, history points to the importance of collective action as a means for individuals to secure improved outcomes for themselves and their communities. In the nineteenth century, for example, the right to vote was available only to landowners in the UK, leaving most of the population shut out of the political system. In response, individuals pooled their economic resources to create land societies, collecting purchasing plots of land that were then divided between the society's members, giving each member the right to vote.<sup>22</sup>

Inspired by this history, data trusts have emerged as a new model for data stewardship.

Trust law has long been used in the UK to establish the rights and responsibilities different parties have in relation to an asset. Based on this framework, a data trust is a mechanism for individuals to take the data rights that are set out in law and pool them into an organisation – a trust – in which trustees make decisions about data use on their behalf. Those trustees would be bound by strict fiduciary responsibilities, demanding that they steward resources held in the trust for the benefit of its members with undivided loyalty, prudence, and transparency.

Bound by these obligations, data trustees would exercise the data rights conferred by existing regulations (such as the EU's General Data Protection Regulation) on behalf of the trust's beneficiaries. They would act as an independent intermediary in negotiations about data use, working on behalf on the trust's beneficiaries. The trustees would seek to leverage the bargaining power associated with the aggregation of data or rights in the trust to seek more favourable terms of use than any individual alone would be able to pursue. If failing in their duties, trustees could be held to account by the overseeing court, with this court providing safeguards that go beyond those available through other data sharing structures.<sup>23</sup>

Data trusts have received widespread attention in recent years from policy makers across the world, but have yet to be successfully developed in practice. Moving from theory to practice will require further action to translate current policy debates into action, identifying best practices that can inform the design of data trusts, and pilot projects that can trial these ways of working in practice.<sup>24</sup>

In making this shift from theory to practice, recent attempts to establish alternative data institutions offer insights into how real-world data trusts could function. For example, Driver's Seat, a driver-owned co-operative for gig workers offering rideshare or delivery services, has created a platform that aggregates data about its members' working patterns and earnings. By pooling data resources, those members access insights that can help them secure improved working conditions – demonstrating the value of an independent platform that enables collective action.

Recent history also furnishes examples of how the term 'data trust' can be co-opted to promote data governance practices that fail to reflect the aspirations of data trusts as a tool for empowerment. Sidewalk Labs, for instance, set out to create an urban data trust to govern data collected across a waterfront development in Toronto. It proposed to de-identify data at source, then create an independent public authority to manage its use. However, the suggested terms of data use did not account for citizen concerns about surveillance, consent and accountability. The project's failure underlines the importance of creating data trusts in ways that respond to citizen needs and concerns.<sup>25</sup>

# Conclusion: data trusts and citizen engagement

As individuals generate increasing volumes of happenstance data from a growing range of digitally mediated daily activities, there will be new opportunities to use such data for economic and social benefit. Achieving these benefits will require continued public confidence in data use, through data governance systems that are designed for citizens' needs, interests and benefit. Embedding these interests in data governance requires new data institutions.

By creating independent intermediaries to represent the interests of their members in negotiations about data use, data trusts could fill today's gap in the governance environment. Data trusts could provide a sustained infrastructure for bringing citizen voices into policy making:

- The process of defining the terms of a trust is an opportunity for citizens to define the purposes for which they would like to see their data used, and the types of influence they wish to have in decisions about data use.
- The collectivisation of data rights within a trust brings with it increased bargaining power, empowering citizens with more influence in negotiations about the terms of data use than any individual alone could achieve.
- The creation of a trustee as an independent intermediary bound by a fiduciary duty to act in the best interests of a trust's beneficiaries, and acting within the guardrails of strong institutional safeguards – provides a new structure to represent citizen interests and concerns about data use.

Complementing the regulatory regimes that already exist in many countries, these new 'bottom-up' institutions would seek to empower individual citizens to influence the terms under which data about them may be used. In the process, data trusts could help re-orientate data governance around the questions that are central to the public interest – questions about the purpose of data use and who benefits as a result.

Core to the success of data trusts will be the ability to understand and respond to citizen interests. The next phase of data trust development will need to identify what different publics want from data use; what structures or institutions would be considered trustworthy; and what purposes these

new data institutions should be seeking to promote. Effective citizen engagement will be central to these efforts. Data trusts will need to:

- Understand demand, identifying areas where data trusts could play a role in fulfilling citizen needs.
- Identify ways of working and systems of accountability that ensure trustworthiness is embedded in the work of the trust and trustees.
- Create platforms for engagement between beneficiaries and trustees that enable dialogue, and that facilitate widespread participation across all members of society.
- Negotiate competing interests or incentives between individuals or groups involved in the trust.
- Design decision-making procedures within the trust that ensure it acts for the benefit of all its members.

If successful, these new data institutions could fill an important gap in the data stewardship landscape, representing citizen interests or concerns in discussions about data access and use. In the context of crisis response, such institutions could enable rapid use of data to inform policy development in directions that reflect the values, interests and attitudes to risk of their beneficiaries.

Today's digital environment is one of asymmetric power. While current legislation provides a constellation of data rights for individuals, for many the levers to exercise these rights remain out of reach. Data trusts offer a new lever for citizens to set the terms of data use, bridging the agency gap between the imperative to protect individual rights and the desire to use data for beneficial social and economic outcomes.

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- Analysis of 5 billion payment card transactions in France to understand the impact of COVID-19 on consumer spending, made possible by co-operation between banks and public authorities in France
- The use of anonymised, aggregated datasets to understand patterns of mobility or public space use in the UK.

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# Why is it so difficult to integrate citizen science into practice?

# **Muki Haklay**

The term 'citizen science' includes many forms of public participation in research. These range from participating in a search for a cure for cancer by allowing scientists to utilise unused computing resources with little ongoing attention by the participant, to participation in all stages of the scientific process including shaping the research question. It is, therefore, unsurprising that a wide range of issues emerge regarding the integration of citizen science into decision-making processes or policy implementation.

Even if we focus solely on one of the most often acknowledged outputs of citizen science – the production of data at scale – we can see difficulties in its uptake and integration by governmental bodies, and marked differences in the use of citizen science compared to other approaches for information gathering. By and large, there is an expectation that government data gathered by traditional means is of high quality. Questions over the quality of data for decision making emerge occasionally (e.g. the missing million men in the 2001 UK census,<sup>1</sup> or the discussion on how to count deaths as a result of the COVID-19 pandemic<sup>2</sup>), but these are rare exceptions given how much data is routinely used by local and national governments.

However, it is much more common to encounter concerns over data quality when citizen science or crowdsourcing are involved.<sup>3</sup> (We will use the term 'crowdsourcing' in addition to 'citizen science' since the two overlap, and, especially in the context of data creation, are often used interchangeably.<sup>4</sup>) This questioning of data quality is somewhat puzzling when we consider

that the use of citizen-science data as part of government practice is not new. Every day for at least 150 years, meteorological services across the world have received weather observations from far and wide that are contributed by volunteers.<sup>5</sup> The same is true for research institutions – from William Whewell's great tide experiment of 1835, which included thousands of observers,<sup>6</sup> to the history of biological recording of different species by amateurs, which also goes back hundreds of years.<sup>7</sup>

Why, then, do we need to advocate the integration of citizen-science data in government and research institutions? Why is it that in the third decade of the 21st century, we need to create special incentives and plans to encourage such bodies to open up to the public, and for scientists to integrate the capacity of public observers in their work?

# Understanding the institutional challenges

To understand the institutional resistance and consider how to overcome it, we need to look at several issues that are central to the utilisation of citizen-science data within governmental bodies.

Firstly, consider the maxim 'organisations do not use crowdsourcing because they want to, but because they have to'. In the cases of weather and biological recording, it is prohibitively expensive to locate observers with the necessary geographical distribution; even the location and maintenance of automated sensors will be too costly. In other cases, too, it is budget constraints that push organisations towards such methods of data collection. Compare the relatively well-funded US Census Bureau to the less-well-funded US Geological Survey (USGS). When the Census Bureau updated its maps, it used its employees for comparing its maps to recent satellite images – a task that can be done well with volunteers, and is the basis of projects such as OpenStreetMap.<sup>8</sup> In contrast, USGS uses a volunteer programme, the well-established National Map Corps, to update its maps – because in some cases, due to budget limitations, these were not updated for 20 years or more.

In these situations, an organisation may consider that a task should be managed internally if it can be, even if this will entail missing out on benefits from citizen science (such as the utilisation of local knowledge), and prefer to rely on existing resources and practices. This is unless an external force – such as a regulatory requirement, or a decision by someone who is in charge of the organisation's activities (e.g., a minister) – pushes the organisation to adopt citizen science.

Secondly, many governmental practices of data collection evolved from command-and-control structures, and therefore the in-built messiness in citizen science, and other activities that rely on open calls, are conceptually challenging. Many government organisations have created industrial processes for data collection, as a standardised and routinised process can be automated to better use limited resources.

Endorsing citizen science processes, by contrast, requires a change in mindset about the production and use of data. For example, the quality of the interface for a publicly open system needs to be much better than for an equivalent intra-organisation one. We are all familiar with intraorganisation computer systems with hard-to-use interfaces; such difficult interfaces persist because an organisation can compel its employees to use these systems to fulfil their jobs, and because the number of employees using the system might be relatively small, so that the organisation can rely on tacit knowledge and peer support to make the system operational and produce good-quality information. In contrast, a public-facing system needs to support a short learning curve, by a large group of people with a range of skills and backgrounds. The system and its interface must also be designed to support the process of entering high-quality data – and that might require careful design and testing of the workflow process.

Quality-assurance processes also require a different approach in citizenscience projects; encouraging wider use of citizen-science practices may require both awareness-raising and implementation support. Concerns about data quality, for example, may be alleviated through the inclusion of an 'expert in the loop'. We can see the role of the UK's Biological Records Centre (BRC) as exactly that. The BRC is an interface between the scientific and governmental system (which needs the data from many recording schemes that are carried out across the country) and the needs and interests of the volunteers and the organisations that support them. With a very small team, the BRC provides the scientific interface which facilitates the integration and use of citizen-science data for policy.



Dr Helen Roy shows Defra Minister Richard Benyon the Biological Records Centre's UK Ladybird Survey (<u>https://www.brc.ac.uk/scheme/uk-ladybird-survey</u>) – which has received thousands of records from volunteers.

Thirdly, governmental organisations operate within a legal and regulatory environment that has evolved over time. Data collection and use are frequently linked to obligations for monitoring a condition or delivering an agreed policy, as in the case of environmental monitoring against acceptable levels of pollutants. Another example is the agreed service standards of mapping agencies, such as the commitment of the Ordnance Survey to update a major change to the landscape within a given period of time. Moreover, many governmental data-collection activities are impacted indirectly by laws in other domains of government activity. For example, in the US, the 1995 Paperwork Reduction Act stipulates a need for approval for requesting information from the public; this is done by a single crossgovernment committee in a complex and lengthy process, representing a barrier to the use of citizen science by the federal government.<sup>9</sup> The 2016 Crowdsourcing and Citizen Science Act,<sup>10</sup> a specific law enacted to alleviate such barriers, stands as an example of legislative action to address regulatory and legal limitations on the use of citizen science in government.

A number of other factors have been identified as contributors to the acceptance of citizen science and crowdsourced information in government.<sup>11</sup> For example:

- The role of 'champions' inside governmental organisations individuals willing to encourage their colleagues and managers to integrate citizen-science data in the work of the organisation
- The value of working with intermediary organisations with experience in running and utilising such methodologies, and using their experience in training staff in how to develop such activities
- 'Trigger events', frequently linked to some sort of emergency, which open up both the need and the willingness to utilise alternative sources of data; natural and human-made disasters, as well as major outbreaks such as COVID-19, are such events, as the example of Safecast in Japan demonstrates.

Finally, however, we also need to recognise a major cultural obstacle within scientific practice itself, one which is based on perceptions and anxieties about the special role of scientists and experts in policy making and implementation – that is, the view that opening up decision-making and monitoring processes risks letting in the 'barbarians at the gate'.

Since the end of the Second World War, scientists have established themselves in relation to wider society as an autonomous and exclusive group of knowledge producers<sup>12</sup> – especially when it comes to decision making processes. They might be issue advocates, honest brokers, or communicators of the latest science<sup>13</sup> – but in all these variations, it is the scientific community that is in charge of creating scientific knowledge. Research shows that only a small group of researchers communicate their research to the public.<sup>14</sup> Moreover, when asked about it, scientists often do not see citizen science as an appropriate methodology, and if given a choice and funding, would prefer to carry out their studies without public involvement.<sup>15</sup>

The cultural objection for opening up to public participation in the scientific process is also linked to concerns about status and acceptance of expertise, and respect towards scientists.<sup>16</sup> These concerns may be linked to the data-quality issue ("only a qualified scientist can collect the data properly"), suspicions about motivation ("only a practising scientist can understand the principles of objective and disinterested research"), or concerns about social standing, secured streams of funding for vital scientific work, and job security. Despite cultural changes that are aimed at internal scientific practices, such as the move towards open access publications, the resistance runs deep, and persistent push from research funders is required if behaviour is to change. Citizen science represents the opening up of practices that are mature and comfortable to those who are involved in them, and it is therefore not surprising to encounter significant resistance. This issue can be addressed both by encouragement from research funders and science policy makers, as well as through the provision of appropriate guidelines and support to champions who are changing the practice from within.

# **Overcoming the challenges**

In summary, the acceptance of citizen-science data is linked to individual perceptions, organisational practices, skills, legal framework, and cultural factors. Many of these challenges apply beyond our focus on data collection and are relevant to other forms of citizen science; they can also explain why more comprehensive forms of participation – where the public is also influencing the research question, the analysis, or the use of the resulting information – can present more challenges and face strong resistance. All these are changing, but it is not surprising that the pace of change is slow.

The UK is fortunate to have a long and distinguished history of citizen science, a strong sense of public interest and trust in science, and a history

of innovation in this area. Witness this history of achievements (some of them touched on above), all of which have policy implications: Whewell's tides experiment in 1835; the Met Office's observations since the 1850s that culminate in 13 million records on Weather Observation Website today, providing the UK with excellent weather forecasting with high economic value; the sustained effort of the BRC over the past 50 years, with over 80 recording schemes and the sharing of data with government; the creation in 2004 of OpenStreetMap, which is now used by the likes of Facebook and Microsoft; the engagement of over one million students through the Open Air Laboratories (OPAL) project from 2007 to 2019; and the establishment of the Zooniverse platform in 2007 with its one-million-plus volunteers. The UK is also the home of Big Garden Birdwatch, which has engaged millions of people in observing birds since 1979 and is now the largest wildlife survey in the world. All these initiatives demonstrate the UK's existing expertise, knowledge, and infrastructure in citizen science.



Big Garden Birdwatch has engaged millions of people in observing birds since 1979, and is the largest wildlife survey in the world.

At a time when many countries and international organisations are engaging with citizen science, there is an opportunity to capitalise on this social, professional, and physical infrastructure, and integrate it into practices that are required for sustainable living in a highly educated society. By putting the necessary regulations, incentives, and support in place, many opportunities can be opened up. These might include:

- Transforming education and increasing public knowledge of science, which is now critical to making sense of the world and acting as active citizens in society
- Addressing health challenges through the participation of patients and community in collecting information as well as agreeing on courses of action to address issues such as obesity or child health
- Providing the data needed to understand environmental change, and to engage people in climate adaptation and actions to address its challenges.

None of the barriers outlined in this paper is insurmountable; all can be addressed with carefully designed interventions that will resonate in other forms of participatory governance.

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Acknowledgements: the research was supported by European Union's Horizon 2020 research and innovation programme under grant agreement No. 824580, project EU-Citizen.Science (The Platform for Sharing, Initiating, and Learning Citizen Science in Europe), grant agreement No. 101006201, project TIME4CS (Supporting Sustainable Institutional Changes to promote Citizen Science in Science and Technology), by the ERC under grant agreement No. 694767, project European Citizen Science: Analysis and Visualisation, and by the Natural Environment Research Council under grant No. NE/S017437/1.

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# Future directions for citizen science and public policy

Edited by Katie Cohen and Robert Doubleday

The past decade has seen a growing imperative in government to find new ways to involve citizens as partners in the development and delivery of policy. At the same time, we have seen a flourishing of citizen science experiments and the increasing embrace of these approaches by scientific communities. But to date there have been surprisingly few experiments with citizen science by government itself.

Citizen science has made vital contributions during the COVID-19 pandemic. As the UK government continues to navigate a way through the challenges posed by the pandemic, it is important to consider how citizens' knowledge can continue to make a more active contribution to science and government.

To support these efforts, this collection brings together new essays by policy makers, scientists, practitioners and scholars, with a foreword by UK Government Chief Scientific Adviser **Sir Patrick Vallance**. Authors draw on a wide range of insights including from **Zooniverse**, **Citizen Sense**, **THIS Institute**, **Sortition Foundation**, **Food Standards Agency** and **Copenhagen Business School**.

This project is a collaborative initiative of the University of Cambridge's Centre for Science and Policy (CSaP) and the Expertise Under Pressure research project, funded by THE NEW INSTITUTE and hosted by the University of Cambridge Centre for Research in the Arts, Social Sciences and Humanities.

"I am very grateful to CSaP for bringing together this diverse group of authors to share their experience of citizen science, enabling us all to better understand the potential it has to contribute to public policy."



Sir Patrick Vallance



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