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From the bench to public policy: Enhancing public trust in science

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Abstract

There is growing concern around the world about declining trust in the scientific enterprise. Some STS scholars argue that the solution is to move to a system of 'virtual diversity' where scientists are responsible for translating public concerns into their work. This commentary argues that this containment approach will have the opposite effect. The history of similar efforts suggests that scientists have trouble understanding the scope and urgency of public frustrations, and devalue the contributions of non-scientists, damaging the social fabric. A better approach for producing socially useful science and enhancing public trust is to create a truly inclusive scientific enterprise, which takes the knowledge and priorities of non-scientists seriously and engages them throughout the investigative process.

Keywords

expertise, science, public trust, activism, evidence-based policy, diversity, Flint, intellectual property

This feels like a particularly precarious moment for the sciences. Falsehoods now regularly masquerade as facts, buoyed by social media algorithms and political leaders. In many countries, government responses to the COVID-19 pandemic fostered public distrust in both public health and scientific advice (Pearson, 2024; Pew Research Center, 2024; Seyd et al., 2024). There is great concern about the outsized power and wealth of the pharmaceutical and tech industries (e.g. Bharti & Sismondo, 2024; Crawford, 2021; Goldenberg, 2021). In the United States, this has come to a head with Donald Trump's

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choices to lead multiple government agencies in his second presidential term, including the nomination of conspiracy theorist and vaccine skeptic Robert F. Kennedy Jr. to lead the Department of Health and Human Services, which oversees both the Centers for Disease Control and Prevention and the National Institutes of Health. Trump and Kennedy's plans for the NIH include replacing hundreds of employees and sending some of the research budget to states to disperse as block grants (Rosenbluth & Anthes, 2024; Stein, 2024).

For many STS and other scholars, the answer to this breakdown in scientific—and social—trust is to diversify the scientific enterprise. This means supporting people from marginalized communities to pursue scientific training (Imbler, 2021; Tallbear, 2017), but also inviting non-scientists to participate throughout the scientific process, from shaping research questions to designing technologies to advising policymakers about how to incorporate their knowledge into evidence-based decisionmaking (Costanza-Chock, 2020; Hsu et al., 2017; Parthasarathy & Katzman, 2024; Ottinger, 2010; Shamasunder et al., 2022). This approach, they argue, will produce more inclusive science that strengthens its utility for policymakers, physicians, and civil society among others. Ultimately, they hope it will enhance public trust.

For Collins, Evans, and Reyes-Galindo (CE&RG), this poses risks. They suggest that 'failing to *exclude* voices from the scientific debate' will prevent the validation of facts (scientific 'closure') and could destroy science as a 'distinct' social institution (p. 2). This will ultimately harm citizens, they argue, presumably because we will no longer know which facts to follow, and accelerate the slide towards fascism, because without the external check that science provides people will increasingly turn towards charismatic leaders like Trump, Orban, and Bolsonaro. Instead of incorporating outsiders into the scientific process, CE&RG advocates for 'virtual diversity' as a new scientific norm, which involves 'discovering the cultural truth about initially alien groups … to be accomplished with the same assiduousness as the pursuit of truth in the rest of science' (p. 11). Scientists, they argue, should be responsible for listening to non-scientific communities about their concerns and then translating them to their colleagues and into their studies to improve science.

At first glance, this seems like a fine proposal. After all, scientists who tell their peers about the needs, frustrations, insights, and lived experiences of relevant communities are likely to have greater impact than individuals from the communities themselves, not just because they speak the same language but because they will be viewed as more credible. Further, putting this burden on scientists could actually bring in more non-scientist knowledge, since many publics lack the time and resources to try to influence science even on matters important to them.

The idea of 'virtual diversity' to bring public concerns into science is not new. Throughout the 20th century, governments invested in scientific research and infrastructure—including employing technically-trained bureaucrats and assembling expert advisory committees—that incorporated science's seemingly neutral, objective insights into policymaking (Ezrahi, 1990; Jasanoff, 1998; Kleinman, 1995; Mukerji, 1990). But this approach became increasingly controversial with the rise of civil society, as citizens pointed out the biases, limitations, and problems of science itself, and thus the evidence that informed important government decisions (Jasper, 2014; Lerner, 2001; Nelson,

2015; Sabin, 2021; Stark, 2012). In response, governments added procedures that resemble CE&RG's 'virtual diversity': for example, advisory committees that make recommendations on a wide variety of issues including public health, infrastructure development, environmental impact, research ethics and funding, and even pharmaceutical approvals must listen to public testimonies and read public comments, and consider them in their decisions (Espeland, 2000; Grisinger, 2012). This includes, for example, the committees that determined what kinds of HIV/AIDS research should be conducted and how, and which pharmaceuticals should be approved to mitigate the disease, in the early days of that epidemic (Epstein, 1998). Governments hoped that this approach demonstrated their interest in hearing public concern while keeping it contained, maintaining the objectivity of science and therefore, public policymaking.

This legacy teaches us that by excluding the *real* diversity that non-scientists provide, 'virtual diversity' cannot solve the problem of public distrust in science, and may even damage it further. First, although virtual diversity is designed to incorporate public concerns into science, it erases the emotion, urgency, and complex understanding of problems and solutions that usually characterize the interventions of affected communities. This can distort scientists' understandings and provoke backlash. US-based HIV/AIDS activists had great impact not just because they learned the science as CE&RG suggest, but because they used disruptive, even shocking, protest tactics over and over again to make the devastating consequences of the disease clear at a moment when the Reagan administration was content to ignore it (Epstein, 1995, 1998). Similarly, consider long COVID, a disease that entered scientific consciousness only because sufferers used social media to find one another, crowdsource disease etiology, and pressure scientists, physicians, and governments to hear their concerns. In fact, even though scientists had begun to pay attention to the disease by May 2020—including an account in the *British Medical Journal* published by an infectious disease professor—the World Health Organization's COVID-19 Technical Lead still referred to it as 'mild' and supported by 'very little evidence' (Callard & Perego, 2021). It took patient advocates, who were sometimes unruly, to convince scientific and medical agencies that it was a serious disease of its own and warranted attention. In the US, Congress then allocated over $1 billion to NIH to study the disease. But patients soon became frustrated that the agency was 'taking on vague, open-ended research questions rather than testing out therapies or treatments …' (Zhang, 2022). Even when they heard the concerns of patients and acted upon them, experts made choices that privileged scientific priorities. As a result, long COVID activists began to view even seemingly friendly scientists as untrustworthy obstacles.

The Flint, Michigan water crisis offers a similar lesson. After officials switched the city's water supply from the Detroit River to the Flint River in 2014, residents noticed serious problems. Not only was the water discolored and smelly, but it caused rashes and hair to fall out, among other symptoms. For months, they complained to city, state, and even national experts, who dismissed their concerns as hysterical (Pauli, 2019). Finally, they captured the attention of Virginia Tech professor and lead-in-water specialist Marc Edwards, who concluded that Flint River water was so contaminated that it had leached lead from the pipes and caused the health problems. Edwards was exactly the type of translator that CE&RG envisions, and his intervention led Flint to switch its water supply

back to the Detroit River, begin to repair its pipes, and develop programs to support the children who ingested lead at important developmental stages. But Edwards was so focused on the lead problem—after all, this was his central area of expertise—that he would not acknowledge residents' concerns that the contaminated water had also triggered an outbreak of Legionnaire's Disease, which killed dozens of residents and sickened many more (Binney et al., 2019; Pauli, 2019; Zahran et al., 2018). Instead, he tried to diminish the activists' credibility, which increased many citizens' distrust of scientists. As with long COVID, the 'virtual diversity' achieved through Edwards' translations did not properly capture residents' concerns and frustrations, with devastating consequences for public health and social trust. For years after the crisis, despite reassurances from scientists and government officials and replacement of the lead pipes, residents questioned the water's safety and relied on expensive bottled water (Sarathchandra & Taylor, 2024). Further, their skepticism of public health and scientific advice made them more vulnerable to the COVID-19 pandemic (Ezell et al., 2021).

Second, as scientists engage in 'virtual diversity' they may take credit for lay knowledge and data, frustrating publics. Receiving credit for new ideas, through citations, patents, awards, media profiles, and even social media followers, is central to a scientist's career and indicates one's prominence. For decades, if not centuries, scientists have learned from publics and then translated these insights into publications and technologies with no credit and little benefit flowing back to the original knowers (Bulstrode, 2023; Hayden, 2003; Thurner & Cañizares-Esguerra, 2023). But today, as citizens become more aware of the value of their knowledge and data to both science and commerce, and as science becomes more central to our everyday lives, many are no longer content to inform science—or put differently, provide the insights that constitute 'virtual diversity'—without some type of recognition (Kahn, 2000; Skloot, 2011). Flint residents were deeply frustrated that Edwards not only shifted public attention away from the Legionnaire's Disease outbreak, but that he also seemed to take credit for identifying the problem with the contaminated water (Pauli, 2019). After all, *they* had identified the problem and solicited help from technical experts, including him. In the wake of the crisis, scientists flocked to the city to conduct research. One Flint-based community health activist reflected on her experiences: 'As community members, we also see our ideas appropriated. For instance, during a discussion at one national meeting, I made a distinction—on the basis of my own experience—between projects that were faith-based (driven by religious principles) and those that were faith-placed (using spaces such as churches). The following year, a researcher presented data based on this model without acknowledging me as the inspiration. I felt dishonoured, discouraged and demotivated' (Lewis & Sadler, 2021). She noted further that this changed the way she interacts with scientists: 'I now ask academic partners to give attribution for my ideas. Knowing the norms—and what credit to request—has helped me immeasurably' (Lewis & Sadler, 2021).

This 'appropriation' concern is particularly acute in attempts to patent human biomaterials, including genes, and indigenous knowledge (Foster, 2017; Harry, 2009; Merz et al., 2002; Parthasarathy, 2007, 2017). For example, as scientists developed techniques to map and sequence human genes and identify disease-causing mutations in the 1990s and into the 2000s, patients and their families lobbied them to identify the

genetic causes of the diseases affecting their lives. In return, they provided scientists with information about their family and disease histories, blood and tissue samples, activated their networks to find other research subjects, and even sometimes raised funds for research. But once scientists identified the problematic genes, they and their institutions often patented them. The patent holders and licensees then charged high prices for access to any resulting technologies, including genetic tests and treatments. This led to tremendous frustration, and in some cases lawsuits, among the people who had provided what they considered data and knowledge (Colaianni et al., 2010; Park, 2018).

CE&RG might respond to these conflicts by suggesting that virtual diversity efforts simply need to be improved, perhaps facilitated by clear standards. But such standards would be extremely difficult to develop and police, and the above cases make clear that the costs of violations are high for the well-being of vulnerable communities as well as for already fragile public trust in science. It is also challenging to imagine how the scientific enterprise would exclude demanding, and even unruly, publics in practice, especially in places with robust civil societies. Publics increasingly provide the data that powers the engines of science—from epidemic surveillance to artificial intelligence—and are influenced and sometimes even disciplined by its findings. Given these consequences for their lives, it is not surprising that they seek to influence the construction of science and its social meaning. And when they go unheard, they often adopt adversarial means. Restricting this engagement could destroy the social fabric that remains. Public participation is the cost and benefit of life in democratic societies.

Further, proponents of a more diverse science hope that a deliberately inclusive investigative terrain will reduce the temperature of discord between scientists and non-scientists. In other words, efforts to expand demographic diversity in science are not just moral and epistemological, as CE&RG suggest, but also political. Centering public—and particularly historically marginalized communities'—priorities in the research questions asked, methods used, technologies developed, and the types of evidence that inform policymaking, for examples, will produce science that benefits more people while making it more difficult for opponents to challenge. It will be more useful and robust. And perhaps, cultivating greater trust in science using these methods will set the stage for repairing social trust on a broader scale for the long term.

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