

# Innovation as a Force for Equity

Today's health innovation system doesn't benefit everyone equally. To change it we need to think differently about expertise, innovation, and systems for ensuring access to crucial technologies.

**A**s we plan our science and innovation policy strategy for the next 75 years, we must work to center equity as a public value. Today, the United States is profoundly unequal, with 10% of households holding 76% of the wealth. The net worth of a typical white family is 8 times its Black counterpart and 5 times its Hispanic counterpart—and these disparities have not changed much over the last 30 years. Meanwhile, close to one half of all households in the United States have less wealth today than the median household had in the 1970s. Furthermore, the life expectancy for the wealthiest 1% of individuals in the United States is far higher than for the poorest 1%: 10.1 years more for women and 14.6 for men.

Historically, the US government has focused on policies designed to stimulate innovation in the hope that these policies would generate markets, produce macroeconomic growth, and provide access to new technologies. One of the first priorities of our nation's founders, notably, was to build a strong and predictable patent system that encouraged broad participation.

Over a century later, Vannevar Bush, director of the US Office of Scientific Research and Development, built upon this approach. His 1945 report, *Science, the Endless Frontier*, commissioned by President Roosevelt, encouraged the government to turn away from the mission-driven science that had supported World War II and instead trust scientific priorities to serve the public good.

In response, policymakers have made significant investments in basic scientific research through the National Science Foundation and the National Institutes of Health (NIH). Scientists guide the allocation of research funding through both priority setting and peer review. And the government largely has relinquished to universities and the private sector any intellectual property (IP) interest in the technologies that result from its funding in the hope that this will stimulate market activity. The assumptions are clear:

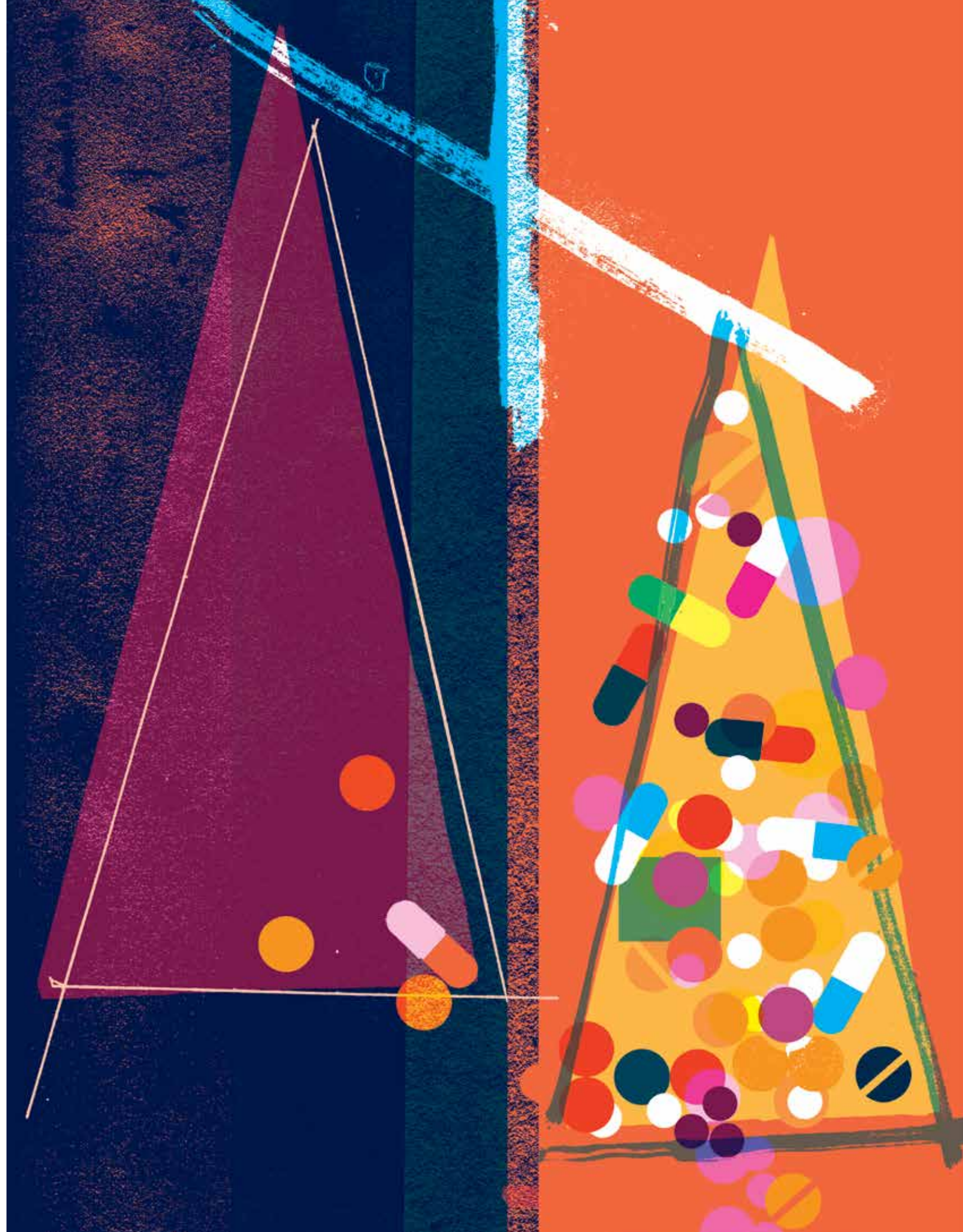
innovation, by its very nature, is socially beneficial, and the government's role is to foster innovation through research, translation to the private sector, and a robust patent system. And by many measures it has been successful.

But innovation isn't benefiting everyone, and sometimes it amplifies inequality. Whether the internet or insulin, many people in the United States lack access to crucial innovations. Meanwhile, machine learning algorithms and many other technologies reflect and reproduce social biases, including racial biases. Better public policies, however, can help to address these problems and ensure a more equitable and just twenty-first century.

## **Distinguishing innovation from health care**

According to one review, between 1970 and 2009, government resources directly contributed to the discovery of 153 drugs and vaccines. But these diagnostics, devices, and treatments are often inaccessible to the most vulnerable. In some instances, they are extraordinarily expensive, making them unaffordable. Other innovations such as cancer screening technologies may be relatively affordable, but they are not distributed equitably. Some observers might argue that this is the fault of our decentralized, privatized health care system. But characterizing these as problems of health care rather than innovation is itself a political choice that is shaped by a circumscribed understanding of innovation that focuses solely on scientific and economic output. This choice has real costs for communities.

Patent policies and practices, for example, facilitate private sector efforts to build and maintain monopolies over inventions, and then charge extremely high prices for access. Consider the case of hepatitis C, which affects approximately 3.5 million people nationwide, of whom 20% develop severe complications that can require medication, hospitalization,



and liver transplant. In recent years, the US Food and Drug Administration (FDA) has approved a handful of new drugs to treat the disease. The new treatments are quite effective, but because they are patented and there are very few options available, the companies can charge astronomical prices: from \$84,000 to \$95,000 for a 12-week regimen. This ultimately limits their use. And while the life of a patent is only 20 years, companies file multiple patents on different components of the drugs to extend their monopolies. One analysis found that for each of the top 12 grossing drugs in the United States, companies attempted an average of 38 years of patent life.

These problems aren't limited to the patent system. Agencies that fund research shoulder responsibility as well because, imagining that an unfettered marketplace is the primary way to distribute innovation, they refuse to assert their authority to influence markets. In 1980, the US Congress passed the Bayh-Dole Act, which clarified that universities could hold patents on the fruits of federally funded research conducted by their employees. Universities could now patent inventions at early stages and license them to companies, who would use additional patents, trade secrets, and proprietary tacit knowledge to strengthen their market position. Congress acknowledged, however, that there might be instances where patents might contravene the public interest. So Bayh-Dole established a "march-in" right that allowed the government to step in if the patent holder did not adequately commercialize the product, and force universities or small businesses to license the innovation to additional companies.

To date, however, federal agencies have never exercised this right. For example, NIH and Department of Defense (DOD) provided grant funding for the development of Xtandi, a prostate cancer drug developed by researchers at the University of California, Los Angeles (UCLA). UCLA patented the compounds and sold them to a Japanese firm, which markets the drug for over \$129,000 per year per US patient—a much higher price than in other high-income countries. Despite efforts from civil society groups and federal legislators, DOD has refused to use its march-in rights. DOD argues that although the drug is costly, it is widely available—and therefore public health and safety needs are being met.

High prices aren't the only issue. Even when prices are reasonable, markets may still distribute innovation inequitably. This imbalance becomes even worse when supplies are scarce. At the beginning of the COVID-19 pandemic, both public and private sector laboratories across the United States rapidly developed diagnostic tests that could be used to identify people with COVID-19 who needed to isolate themselves to limit disease spread. But even as supply increased, tests remained scarce among marginalized communities despite their disproportionate risk of contracting and dying from the disease.

Again, some observers might argue that these sorts of problems are not the fault of innovation policy but rather the responsibility of markets or health care systems. But NIH itself

acknowledged that vulnerable and historically underserved communities were not able to access COVID-19 diagnostics. In response, NIH created a research funding program (RADx-UP) to address this issue, suggesting that the agency itself recognized its role in and responsibility for the problem.

Unfortunately, programs such as these are reactive and ad hoc, and often focus on health care pricing and access rather than on the design of the technology itself. Policymakers and scientists could instead make systematic efforts to consider these concerns at the roots, when early-stage research is funded and patent rights are awarded. They could make technology design and development choices that maximize equity rather than, for example, market viability. Put simply, innovation and health care equity need to be relinked in our public policies.

### Treating socioeconomic conditions with molecules

Guided by scientists as well as market priorities, innovation-focused institutions prioritize mechanistic investigations that can produce generalizable conclusions and, ultimately, scalable commodities such as molecules or drugs. This focus, in turn, enables what some call "pharmaceuticalization," in which social conditions are turned into individualized, biologically based conditions that the private sector can fix through profitable technology. But this argument can be taken one step further.

By a) investing in research and interventions at the molecular level, b) viewing the marketplace as the primary route for technology to achieve the public good, and c) encouraging expansive patent rights, the US government currently enables the development of commodified solutions that are devoted to treating health problems once they emerge. Such medicalized interventions tend to be more accessible to already privileged groups. But addressing the root causes—including the built infrastructure, working conditions, or environmental pollution—are likely to produce the greatest gains for marginalized communities, and long-term benefits for the population overall.

Consider the example of asthma. Its cause is unclear and there is no cure, but many of the lung disease's triggers are external and specifically environmental, including air pollution, chemical fumes, and dust. It is also strongly associated with poverty. In general, more people are being diagnosed with the disease than in the past, but its prevalence is increasing more rapidly among historically disadvantaged communities of color. These communities are also likely to experience worse disease outcomes, including hospitalization and death. In response, governments have increased research funding, but research has focused primarily on genetic and biological mechanisms rather than on how to transform environmental and socioeconomic conditions necessary to prevent and mitigate disease. This approach fits with both the dominant concerns and approaches of scientists in this field as well as those of the private sector.

## Innovation left undone

The US innovation system has come to represent a narrow range of interests. Vannevar Bush argued that allocating grants on the basis of merit, as defined by peer review, would increase the likelihood of high-quality science and ultimately produce beneficial technologies as well as economic growth. Implementation of this approach, however, has skewed research. Most federal funding goes to a handful of universities in a few states. Harvard University, for example, receives more research funding than all historically Black colleges and universities combined. In addition, women, historically marginalized communities of color, and disabled scientists receive less funding than their white, male, able-bodied counterparts, despite recent targeted initiatives to better balance funding support.

The resulting demographic homogeneity has a real impact on innovation, by shaping the research questions reviewers define as important and the methods seen as appropriate. NIH, for example, is less likely to award R01 grants (grants of larger sums that are needed for a successful research career in the health sciences) to Black investigators than their white counterparts with similar educational backgrounds, training, previous grants, and employers. These researchers tend to investigate less-

The history of the pulse oximeter reveals how this happens. Oximeters measure the amount of oxygen in the blood by calculating how much light is absorbed by human tissue; this technology has been crucial in evaluating patients during the COVID-19 pandemic. Skin tone, however, affects light absorption. When Hewlett-Packard developed the original oximeter in the 1970s, it took care to ensure its accuracy among varying skin tones by testing it among people of color and allowing it to be calibrated according to each individual.

But Hewlett-Packard eventually stepped away from this area of technology, and a small biotech company developed and patented a new version of the pulse oximeter that is now dominant in COVID-19 care and beyond. The new company did not test its device in a range of patients and used its patent rights not only to prevent others from developing devices but also to reject requests for information about its accuracy. This was permitted by the FDA, which has jurisdiction over pharmaceuticals and many medical devices, but focuses narrowly on questions of safety and efficacy. The Patent and Trademark Office (PTO) typically only considers whether a technology is an invention according to the law and what is previously known (i.e., “prior art”).

## For the last 75 years, the “endless frontiers” of science have been defined too narrowly, by too few people, and with incorrect assumptions about the relationship between innovation and societal benefit.

funded topics: their proposals often include topic words—such as *socioeconomic*, *health care*, *disparity*, *lifestyle*, *psychosocial*, *adolescent*, and *risk*—that focus on structural concerns and are less likely to lead to commercializable products. Meanwhile, the proposals that are most likely to be funded include topic words such as *osteoarthritis*, *cartilage*, *prion*, *corneal*, *skin*, *iron*, and *neuron*. Overall, the proposals least likely to be funded are associated with women and reproductive issues.

The consequences of these skewed funding choices, by the country’s main funder of early-stage biomedical and health research, are significant. These choices are further reflected in a society-wide emphasis on mechanistic research, which is more likely to interest the private sector because it can be more easily patented and commercialized. The private sector is less interested in innovation at the community level, in public policy, or in infrastructure. This approach doesn’t only limit our understanding of health inequalities, it perpetuates the false understanding that the solution to health problems lies in individualized, commodified technologies.

## Innovation that amplifies societal biases

In its deferral to the marketplace and reluctance to regulate, the federal government ultimately enables the development and entrenchment of harmful and even biased technologies.

It was only amid the COVID-19 pandemic, when an anthropologist called attention to the problem and a group of physicians conducted a study, that it became clear that the device systematically reported that Black people had a higher blood oxygen level than they actually did—which means they might have erroneously delayed seeking medical care to get needed supplemental oxygen. There have been no studies of the device’s accuracy among other communities of color. The company has not responded to this issue, and although this device is regulated by the FDA, consideration of its potential racial bias is outside the agency’s remit.

No regulator explicitly considered the needs of people of color in the FDA permitting process. And although patents are designed to publicize the technical workings of a device to encourage others to invent beyond it, here the FDA had effectively removed the incentives for others to test or innovate. The oximeter manufacturer was under no legal obligation to reveal its accuracy data. The pulse oximeter remains in common use and is still seen as an essential tool for monitoring COVID-19 at home. Its continued use, however, has likely led to delayed hospitalization and death among people of color around the world.

Some might argue that these issues are matters of regulation rather than innovation. But such a view unnecessarily

constrains the policy levers available. As I discuss in further detail below, agencies that fund science could encourage their grantees to consider whether their technologies might exacerbate inequality and help them to develop more socially just designs. And policymakers might also reconsider the strength of IP protections—especially when they stand in the way of assessing the quality of a technology for all.

### **Innovating for equity**

To address these problems and prioritize equity, society needs to think differently about expertise, innovation itself, and systems for ensuring accessibility to crucial technologies.

**Reconsider who the experts are.** On the subject of health, innovation policy customarily favors the knowledge of biomedical scientists and engineers, physicians, and industry representatives over that of patients, social scientists, ethicists, or historians. But taking equity seriously means ensuring that technologies reflect societal needs and priorities and are also rooted in the realities on the ground. Gaining that perspective requires involving scholars with a deep understanding of equity as well as the affected communities—particularly people in communities who have been historically marginalized—into the earliest stages of the innovation process.

## **Taking equity seriously means ensuring that technologies reflect societal needs and priorities as well as being rooted in the realities on the ground.**

At present, the public has little opportunity to influence innovation policy beyond electing the representatives who make laws and allocate research funding, and occasionally advocating positions through stakeholder organizations. Technologists and policymakers might argue that nontechnical communities lack the requisite knowledge and skills to participate in innovation policy, but this is incorrect. All people are experts in their own needs, lives, and circumstances. If policymakers, scientists, and engineers aim to improve community health, they must begin by understanding the knowledge and priorities of those within the community they seek to help.

Furthermore, in recent years there have been numerous efforts to engage citizens in discussions about highly technical issues. While the exact approach varies, studies show that with the help of background materials, community members are able to grasp technical details. Most are more than capable of questioning experts and building upon their answers. And through deliberative processes, they can offer extremely useful insights to guide policymaking. In the process, participants report that they appreciate exercising their civic duty and feel more engaged in the community.

Communities and social scientists should play a key role in setting priorities at agencies that fund research and at the PTO. These constituencies could be welcomed into advisory

committees that are designed to make recommendations to leaders in the executive and legislative branches, about research needs and priorities as well as fostering innovation in the public interest. This participation includes existing advisory structures. The PTO, for example, convenes a Patent Public Advisory Committee on a quarterly basis with a membership that currently consists entirely of participants from the worlds of patent law and the tech industry. A more representative committee would provide the agency with a deeper understanding of the needs of the citizenry and specifically the health impacts of the patent system.

Furthermore, communities who are affected by policies should be involved directly in day-to-day decisionmaking at innovation policy institutions (such as NIH or the PTO), and should be given some authority in the grant review process. This idea is not new. In the 1990s, women with breast cancer, frustrated by the lack of medical progress in preventing and treating the disease, successfully advocated not only for increased research funding but also for the inclusion of patient voices in grant decisionmaking. They presented the argument that they, as people with the disease, offered a unique understanding of the disease experience and had the necessary expertise to evaluate the impacts of different interventions

to address breast cancer. Today, they regularly participate in scientific peer-review panels. They also successfully convinced Congress to explicitly fund research into environmental causation, departing from NIH's customary focus on mechanistic investigation and commodifiable solutions.

Similarly, in the wake of the recent water crisis in Flint, Michigan, in which residents of the city drank and bathed in water contaminated with lead and bacteria due to the negligence of scientific, political, and policy leaders, researchers and funding poured in to study the effects and offer solutions. But Flint residents were wary: How could they ensure that researchers didn't replicate the racism and mistreatment of previous generations of scientific studies? And how could they make sure the community benefited from the research? As an answer, they created the Healthy Flint Research Coordinating Center (HFRCC), which must approve all research conducted in Flint. HFRCC often suggests changes to proposed studies that would align better with community concerns and context as well as ensures that benefits flow directly back to the community. In return, HFRCC helps connect researchers with funding opportunities.

Bringing communities into the PTO decisionmaking process would look somewhat different. There, citizens might inform technical examiners about the health costs of broadly written

patents, or even remind them of colloquial understandings of novelty and invention. As an example, the European Patent Office has engaged citizens in both town hall meetings and scenario-planning reports. And it is easier for Europeans to register their grievances about specific patents in “opposition” proceedings.

**Reimagine innovation.** Recognizing community and social scientific expertise is a crucial first step in remodeling our innovation system. But we also need to reimagine innovation itself, and the roles of funding agencies in fostering it. The current approach excludes categories of innovation that are likely to be particularly effective in promoting equity and inclusivity such as low-tech interventions and new approaches to public policy, built infrastructure, urban and suburban planning, and pollution prevention and remediation practices. It also fails to recognize innovation by people who have a deep and sophisticated understanding of their social worlds and strong incentives to fix them however they can, but who might lack formal technical training; this category includes nurses, maintenance workers, and individuals in low-income communities.

Research funding agencies can redefine innovation to center equity by spending substantial funds on truly interdisciplinary research that brings together the life sciences, engineering, sociology, public health, economics, and other expertise. This cross-cutting research should take social context seriously in both understanding disease causation and developing solutions to improve health outcomes. Consider, for example, efforts to prevent heart disease and stroke, diseases that disproportionately affect the Black community. Researchers have been working on a variety of solutions, including a mobile health app designed to encourage physical activity and nutrition. Some health experts believed that a properly marketed and distributed app would be useful because it would be commodifiable, could reach a tremendous number of people, and its quality could be controlled.

Interviews with the Black community, however, revealed the technology’s limitations. Accustomed to being disrespected and even harmed by biomedical institutions, interviewees were skeptical of the app. And they revealed a serious barrier to exercise: the lack of safe and accessible outdoor environments in many urban areas. One app, in other words, was not enough to solve the problem. These limitations were revealed early on in development only because of the inclusion of diverse perspectives in the innovation process. This revelation could, with the addition of insights from experts in urban planning and environmental health, lead to more tailored technologies or projects focused on developing innovative infrastructural solutions that would ultimately improve people’s health.

Another reform that could make equity part of early-stage innovation would be to require equity impact assessments as a condition of grant funding. Grant applicants already adhere

to a variety of requirements, such as the National Science Foundation’s expectation that funded projects have “broader impacts” that will serve society. Funding agencies could require applicants to explain how they will evaluate the equity impacts of their proposed project, and how they will address inequities reflected in or amplified by their intervention. This reform could include assessments of whether the design itself is equitable, whether it will be distributed equitably, whether affected communities were consulted in the development of the intervention, and historical analysis of how previous, similar technologies either exacerbated or ameliorated inequality.

Proper implementation of such equity impact assessments would require changes at the level of research projects, grant reviews, and agency staff and programs. To address the requirement, researchers would need to engage members of marginalized communities in their projects as equal partners while also consulting experts who have studied how innovation and equity interact. In their evaluations of equity impacts, they would also need both qualitative and quantitative data. Because of the promise of federal funding, universities would likely provide institutional support for these equity efforts. Agencies would need to diversify the expertise of their grant reviewers, and employ staff with the background to understand and evaluate the equity assessments, facilitate interdisciplinary and community partnerships, and help multidisciplinary research teams ensure their work benefits society. Ultimately, these equity assessments could transform the culture of innovation in a way that individual grant programs focused on diversity, equity, and inclusion could never accomplish.

Funding agencies should also establish offices for community-based innovation. For inspiration, we can look to the National Innovation Foundation in India, which was established by India’s government in 2000 to strengthen “grassroots technological innovations and outstanding traditional knowledge.” The foundation understands that much innovation takes place among those who are “knowledge rich” but “resource poor,” and its first goal is to identify this work where it is taking place. To this end, it offers awards, grants, and loans to people who are developing technologies that might benefit their communities. It also takes special steps to find innovation at the grass roots, through yearly scouting trips to low-resource settings. This initiative, proponents argue, not only makes low-cost, low-tech interventions more widely available but it also empowers communities that traditionally have been marginalized by the innovation system to contribute.

Similar offices within US research agencies could identify and support traditionally unrecognized citizens who are engaged in effective innovation but whose work has traditionally gone unnoticed, and address barriers that may prevent them from applying for funding to develop their creative ideas. This work could embolden these communities to develop solutions that work best for their needs and reveal

unheralded sources and types of innovation. Although these interventions might not be commodifiable or scalable like the technologies discussed above, they are more likely to be accessible to those who need them most. And because they are built from the grass roots, they will be more trusted and sustainable in the community.

**Create new systems for accessibility.** Funding agencies, and the policymakers who guide their priorities, have emphasized the market as the primary mechanism for translating technology to society. Patents and other forms of IP play a key role. But while patents can stimulate innovation in some cases, they can also have an inhibitory effect. And IP can make technologies inaccessible, which is particularly problematic in areas such as health.

Policymakers can address these issues by becoming more sensitive to the circumstances where monopolies might conflict with the public interest, and using the tools at their disposal to resolve these conflicts. This approach could include suspending patents or requiring nonexclusive licenses under specific circumstances, exercising the government's march-in rights, or nationalizing the development of particular kinds of innovation. The PTO could also limit the scope of some types of patents. To create new incentives, the government could provide prizes to innovators who produce, or make substantial contributions toward, innovation that enhances equity. In return, innovators would not maintain any IP interest.

Finally, research funding agencies should create offices that identify and support non-market-based approaches to health innovation. Today, they focus primarily on facilitating the uptake of federally funded research by the marketplace, through technology transfer initiatives at both the national level and inside universities. But there is little investment in translating research that might improve, for example, built infrastructure; pollution remediation programs; or social, environmental, and health policies. These efforts would ensure wider accessibility to the fruits of federally funded research.

The changes suggested throughout this section could be implemented first in the new Advanced Research Projects Agency for Health (ARPA-H) proposed by the Biden administration. Modeled on the famed Defense Advanced Research Projects Agency, ARPA-H is designed to produce breakthrough advances for common diseases. The Biden administration's proposed \$6.5 billion budget is a large and laudable investment, but for ARPA-H to further the administration's strong equity objectives, the program must foster innovation that is based in interdisciplinary and community-based insights and be transferrable beyond the marketplace.

### **Bold, systemic change**

For generations, scientists, engineers, and policymakers have assumed that the US approach to innovation would inevitably produce equity. But it has become clear that this is not the

case, and many people are now advocating for policy change. We are now seeing not only new funding opportunities and programs but also experts in equity and justice positioned at the highest levels of agencies that fund science.

This is not enough. Inequality is baked into the US approach to innovation policy. Driven by scientists' and market priorities, the current approach emphasizes standardizable, scalable, and commodifiable technologies that are designed to work at an individual level rather than benefit communities or address much needed infrastructure failures or policy requirements. Sometimes, this personalized, commodified approach leads to crucial, lifesaving interventions. But often these interventions are inaccessible to the most vulnerable. Institutions involved in innovation policy invariably abdicate responsibility for this disparity. Meanwhile, our society's regulatory ambivalence means that there are essentially no opportunities to correct the social biases and blind spots that are embedded in technologies, ultimately amplifying structural inequities.

Ensuring that innovation policy truly serves all people requires bold, systemic change. We need to fundamentally rethink our understanding of innovation and innovators, upend our assumptions about relevant knowledge and expertise, and reimagine both the government's and the market's role in innovation. For the last 75 years, the "endless frontiers" of science have been defined too narrowly, by too few people, and with incorrect assumptions about the relationship between innovation and societal benefit. To ensure truly equitable progress, we need to leverage a diverse range of knowledge to determine which endless frontiers to investigate and how to study them.

*Shobita Parthasarathy is professor of public policy and women's and gender studies, and cofounder and director of the Science, Technology, and Public Policy Program, at the University of Michigan.*

### RECOMMENDED READING

- Steven Epstein, *Inclusion: The Politics of Difference in Medical Research* (Chicago, IL: University of Chicago Press, 2007).
- Sheila Jasanoff, *The Ethics of Invention: Technology and the Human Future* (New York, NY: W. W. Norton & Company, 2016).
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