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Sasha Henriques worries that the data that guide genetic counsellors are not representative.

THE ACCELERATION OF INEQUALITY RESEARCH

Expertise from multiple disciplines and direct involvement of those affected will help to make inequality research more meaningful. **By Virginia Gewin**

Vida Maralani began her career studying whether education is, in fact, the ticket to socio-economic advancement and reducing inequalities, as she'd been taught. "I've evaluated some of the most expensive social policies our government has ever funded to prevent school drop-outs," says Maralani, interim director of the Center for the Study of Inequality at Cornell University in Ithaca, New York. Yet she found that policies targeted at children in low-income families who were at risk of dropping out of school could only do so much. "These kids were not moving out of their neighbourhoods, and their mums had no more resources than they did before," she says. "The disadvantages that surrounded their community did not change."

Generally, the unequal or unjust distribution of resources and opportunities in a society is studied in just one dimension, such as through income or education, says Maralani. Yet inequalities in income, wealth, education, health and access to technology are inter-related and differ by gender, race, ethnicity and geographical location in important ways. The root causes are multidimensional and dynamic. Some of the most influential work of the past decade – notably French economist Thomas Piketty's 2013 book *Capital in the Twenty-First Century* – demonstrated how persistent inequality has become, even raising international concern (see page 643).

There's an urgency driving increased interest in inequality research. "The reason for it is horrific – inequality is growing," says Melanie Smallman at University College London, who studies how technology contributes to inequality. More than two-thirds of countries are experiencing increased income disparity, which exacerbates the risks of divisions and hampers economic and social development, according to the *United Nations World Social Report 2020* (see go.nature.com/3hpyjkw).

COVID-19 has only raised the bar for inclusive research, because scientists can now assess the impact of the pandemic on those inequalities. Income losses due to the pandemic are estimated to be higher in people paid the least – pushing many deeper into poverty and jeopardizing the prospects of future generations, according to the World Bank.

Not surprisingly, the field is expanding. "The concern that worsening inequality will be long-lasting is one of the key reasons those in the field expand their research often via challenging interdisciplinary approaches – and increasingly through a lens of justice," says Maralani.

As researchers attempt to disentangle the

complex drivers of worsening inequality, the expansion of the sphere of scholars and organizations exploring inequality “is a silver lining”, says Maralani. A lot of people with the right skills are needed to collaborate across fields as disparate as sociology, health and climate change. The challenge, she says, is to go beyond well-worn paths of how we think about inequality and think more holistically.

Take human migration. Demography has long been studied by sociologists, but migration is now influenced heavily by natural resources and climate change. “As we get more data, our ability to study things really expands,” Maralani says. “And as we are better able to share and visualize and describe our data, then our engagement with the public expands.”

Technological change, the decline of trade unions, low minimum wages and the proliferation of no-contract gig jobs are all contributing factors in the continued increase in inequality in the United States since 1980, raising concerns among researchers, policymakers and politicians. One of the UN’s Sustainable Development Goals is to reduce inequality in and between countries. And numerous funders – including the Ford Foundation, the Russell Sage Foundation and the William T. Grant Foundation, all in New York City, and the MacArthur Foundation in Chicago, Illinois – have launched initiatives to “reduce inequality”, and called for researchers to develop evidence-based strategies to meet the goal.

“There’s a broad feeling that this monster is too big for any one academic profession to claim as the job,” says Don Kalb, a social anthropologist at the University of Bergen in Norway. There is also a push to monitor technology shifts in real time to try to prevent inequality from getting even worse. The move away from fossil fuels is a prime example. “The green transition has a very high probability of increasing all sorts of inequalities”, in part because most green-technology leaders are in high-income countries, he says. Researchers need to assess the political tools that might be needed to prevent that source of inequality – particularly given that society now has the capacity to capture real-time data relating to that goal. If successful, the research could even make a leap towards social justice.

Bringing society into research

One goal of inequality research is to make the production of science itself more egalitarian. As interdisciplinary approaches swell to meet growing demand from funding agencies and journals, scientists are grappling with how to meaningfully involve members of the public.

During the ten years that Sasha Henriques was a genetic counsellor in the United Kingdom and South Africa, she had nagging concerns about her work. She wondered whether the data being used to counsel patients about genetic conditions were adequately

representative. And the lack of diversity among counsellors bothered her. To explore the intersection between race, ethnicity, ancestry and genomics, Henriques has started a PhD at the University of Cambridge, UK. “It’s all intersectional,” she says, “nobody belongs to just one group.”

“Without the data, it’s as if inequities don’t exist.”

Henriques’s research will identify when it is relevant to include race in research data, how best to categorize human populations beyond race and ethnicity and how to make the benefits of genomics and health research equitable. But the issues are so complex that Henriques made sure her work was guided by her core value: offering people the tools and information they need to help them understand their genetic risk for disease and make any necessary health and lifestyle decisions – options that have been less available to historically excluded populations.

She advises other inequality researchers, especially those wanting to break into the field, to do the same. “It can feel quite overwhelming to narrow down the research to do something meaningful without going down all sorts of rabbit holes,” says Henriques.

Another key strategy is making sure that oppressed communities are directly involved in the core research design. For example, some health-equity researchers caution that publishing work on historically excluded groups that were not involved in the process



Steven Roberts cautions against research that just pays lip service to inequality.

might lead to specious conclusions that only perpetuate bias¹.

If the goal is to find realistic solutions to inequality, Henriques notes, it is important to bring society into the scientific process. “It can be intentionally embedded within research and research design,” she adds. As Henriques works out how to do that in her research, she has created a website to begin conversations with members of the public (see www.geneticsengage.org).

Bringing people into research prevents the production of science from becoming yet another site of inequality. It also helps to unearth researchers’ hidden biases and ensures greater confidence in the research outcomes. “It matters who produces the knowledge,” says Susanne Koch, a sociologist at the Technical University of Munich in Germany who studies how inequalities shape forest and environmental research.

In May, Koch ran a workshop with environmental researchers from all over the world to discuss the structural issues that can lead to discriminatory research practices. “We need to produce diverse knowledge that is often not put on the table because of social inequalities in academia,” she says. For example, in international forest ecology research, which has conventionally focused on natural resources, it can be “hard for researchers to acknowledge that their knowledge, as is everyone’s, is rooted in their unique contexts”. It struck Koch that colleagues from developing nations said the workshop was the first time they had a chance to address issues that had long bothered them.

Koch says if researchers just produce statistics that show how bad a situation is and then walk away, what incentive do the affected communities have to embrace their findings? “Making this second step after producing the statistics is often missed and what I think is necessary – and, of course, it is difficult.”

A trendy warning

Given the burgeoning interest in inequalities, seasoned researchers worry that newcomers, sometimes viewed as interlopers, will simply tack equity onto projects because it is trendy, and thus end up publishing sub-par analyses. Elle Lett, a social epidemiologist at the University of Pennsylvania in Philadelphia, and her colleagues have referred to such researchers as “health equity tourists”, who are “at risk of polluting the health equity landscape and riddling the academic record with ineffectual, and potentially harmful studies that mischaracterize root causes of health inequities and obfuscate potential solutions”¹.

Steven Roberts, a racial-inequality researcher at Stanford University in California, says that adding an inequality dimension simply to be “trendy” can foster a careless, even reckless, approach that does not engage with issues as deeply and as meaningfully as it



Vida Maralani says there's no simple fix for inequalities driven by complex factors.

should. For example, he says, research focused on a white population might just state that future work will need to factor in diversity, yet offer little description of why that is necessary, what it would look like and why people of colour weren't included in the first place.

Roberts is finishing a sabbatical year at the Russell Sage Foundation, where he is the only psychologist in a cohort of economists, sociologists, political scientists and population-studies researchers who are sharing insights on how their fields investigate inequality. Essentially, each person presents their project – ranging from defining white privilege to identifying racial inequality in scientific publications – and receives crowd-sourced feedback across disciplines. “It’s been the best interdisciplinary experience of my life, and it’s been a rare thing,” he says. Still, he realizes it is difficult to maintain that level of cross-fertilization, especially as an early-career researcher.

And not every facet of the research publication pipeline is equipped to embrace this level of interdisciplinary collaboration. “The more interdisciplinary you are, the better your understanding of the issue and the scope of it, but in terms of communicating that to a non-interdisciplinary audience, it gets tricky,” Roberts says. “My experience is that journals have their lens on their discipline, and you fit into that framework, or you don’t get published,” he says. He is embarking on a project to document publication barriers faced by scientists of colour across the sciences.

Still, like many, Roberts sees inequality research becoming more solutions-focused and thinks it will energize research that transcends disciplines. He says that when

researchers come together to bring their own discipline’s perspectives and methods to the table, “we are in a great position to tackle big problems”.

Data and technology challenges

One of the biggest hurdles for researchers studying inequality in communities is a lack of data. Bonnielin Swenor, director of the Johns Hopkins University Disability Health Research Center in Baltimore, Maryland, who is visually impaired, studies the discrimination and oppression that affects the disabled community – the biggest minority group in the United States, at 67 million adults. In July 2020, Swenor co-authored a plea in *The Lancet Public Health* to include disability information alongside age, race, ethnicity and gender identity when gathering data about COVID-19 – and to make collection of such data routine to create a more equitable society². Incomplete data, she argued, would result in unreliable disease risk estimates.

With US\$1.5 million in financial support from Johns Hopkins, Swenor started a research centre in 2019 to address such data oppression. The centre collects data on disability disparities in employment, education and even COVID-19 vaccine access, and aims to share those data to maximize health and equity for people with all types of disability. “Without the data, it’s as if inequities don’t exist,” she adds.

Smallman agrees. In the wake of COVID-19, she and her colleagues started the UK Pandemic Ethics Accelerator to look retrospectively at the role of data collection in making the effects of COVID-19 better or worse. She notes that 40,000 older people died in care homes in England in the first year of the

pandemic, yet these numbers weren’t released until many months later.

Swenor, like many, distinguishes between inequality and inequity. Inequities – unfairness or bias in a community – leads to inequalities. And that framework goes one step further. “Justice is addressing the reasons why we don’t have equality,” she explains. Swenor says there hasn’t been enough focus on the perspectives of people with disabilities and with other intersecting marginalized and oppressed identities. “If you’re only going to try to solve the equation of inequality with one variable, you’re never going to solve that equation.”

Smallman studies how technology such as artificial intelligence exacerbates inequalities. From driverless cars to robots that harvest crops, many artificial-intelligence innovations aim to replace humans. In doing so, Smallman explains, the wealth generated will be held by a handful of people rather than shared as occurred with past innovations. “The business model of advanced digital technology companies is to drive more inequality,” she says. She advocates for scientists to engage in ethical discussions about how technologies affect individuals and communities, shape institutions and even affect the planet and future generations. “We need to try to stretch out our ethical thinking, so that we can begin to account for these really profound effects that advanced technologies are having,” she says.

One advantage, however, is that improvements in computational power will allow researchers to comb through decades of qualitative data, such as ethnographies and case studies, to gain fresh insights. “We’ll be able to look across case studies and identify patterns which we weren’t able to see before,” she says. And that will be important globally, because inequality is not going to go away, she says, adding that climate change will rapidly accelerate it.

Trying to understand the social determinants of inequality is really humbling, says Maralani. The factors underlying inequalities are dynamic and hard to measure, change over the life course and are passed down through generations. For Kalb, these challenges demand robust scholarship from both veteran and newcomer researchers alike. “We need to brainstorm together,” he says.

To be effective, inequalities researchers will need to move beyond data collection and analysis, says Swenor. They must “dismantle the root cause of the sources of inequities – the policies, the institutions and the systemic issues that create inequities for certain groups,” she says. “That is the future.”

Virginia Gewin is a freelance journalist based in Portland, Oregon.

1. Lett, E. et al. *J. Med. Sys.* **46**, 17 (2022).

2. Reed, N. S., Meeks, L. M. & Swenor, B. K. *Lancet Public Health* **5**, E423 (2020).