BY SARA HARRISON

CAN A CONTROVERSIAL PHILANTHROPIC PHILOSOPHY
NAVIGATE THE THORNY ETHICS OF HUMAN EXPERIMENTATION?



in the U.K. and Africa. "People should have the right to make decisions that affect their lives," he says, and informed people should be allowed to choose which risks they're

U.K. SARS-CoV-2 trial, 1Day Sooner turned out to be three vaccines were all out before the experiment was even done. Institute of Ethics at Georgetown University. "The mRNA days later," says Daniel Sulmasy, director of the Kennedy But things didn't go according to plan. "In the case of the

concept into a flourishing ecosystem of donors, foundathe last two decades, it's grown from a niche, academic effective altruism (EA). EA is based on the premise that inspired by the tenets of a popular philosophy known as tion itself is still cruising along, part of a larger movement accelerate the arrival of COVID vaccines, but the organiza hat will do the most good for the most people. Over: people should use their time, money and energy in ways 1Day Sooner may have missed the chance to help tions and nonprofits.

the disagreements between tive" actions is a complicated Sooner's approach and the history of human medical trials, endeavor. Add in the gruesome Calculating the most "effecprinciples in the real world. enacting EA's seemingly simple plify some of the challenges of real, large-scale change exemorganization's struggle to create But the debate over 1Day

arrived with news that scientists at the University of

Paresh Patel used to be afraid of needles

Then he volunteered to catch COVID-19. When an email

with an ethical conundrum that exposes both the moveglobal pandemic, and you're left experts, and the immediacy of a

risks like blood clots, breathing difficulties, or even death. preexisting conditions, so he wasn't worried about possible And at 27 years old, he was young, fit, and had no a few days, the experience was unremarkable. ment's promise and its potential perils.

2020. Other than losing his senses of smell and taste for He had already caught and survived COVID in October Oxford in the U.K. were looking for volunteers willing to

be infected with the SARS-CoV-2 virus, Patel signed up.

to cure his needle-phobia along the way. study the virus — and do a little amateur exposure therapy needles," he says. Patel hoped that he could help scientists When Patel signed up for the Oxford trial, he became "The only thing, weirdly, that I was worried about was the

19 vaccine, potentially saving millions of lives Sooner believed they would speed the arrival of a COVID. in developing cures for malaria and yellow fever, and 1Day test vaccines and treatments. Such cases have been integral disease so scientists can study their immune response and trials. In these trials, participants are willingly exposed to a that advocates for the wider adoption of human challenge unteered for infection through 1 Day Sooner, a nonprofit one of nearly 40,000 people around the world who vol-

of 1Day Sooner, which is based in the U.S. and has chapters paternalistic, says Josh Morrison, president and co-founder volunteers. The system that regulates clinical trials is overly a congressional briefing, penning op-eds and enrolling duct, 1Day Sooner's founders forged ahead, organizing the trials would be useful — let alone ethical — to con While scientists and ethicists disagreed about whether

> the concept of utilitarianism. In the late 18th and early how much happiness they yielded relative to the amount as much as possible. Actions, therefore, could be judged by individuals to promote happiness and to decrease misery **EFFECTIVE ALTRUISM'S** philosophical roots lie in Bentham proposed that it was in society's best interest for 19th centuries, theorists like John Stuart Mill and Jeremy

of suffering they caused. Crudely put: In utilitarianism, the

ends justify the means.

child drowns. Giving money to standing idly by while a what was then East Bengal Singer compares the article entitled "Famine step further in 1972. In an University, took these ideas a fessor of bioethics at Princeton during a severe famine in Western world's inaction Affluence, and Morality," Peter Singer, a philosopher and pro-John Stuart Mill

case numbers kept climbing. People wanted of the highest infection rates in the world as ute to the greater good seemed like a real, tangible way to contrib to help, and participating in scientific trials The U.K., where Patel lives, claimed some reported to the World Health Organization

remotely by day and video-chatting with His mother worried about him, but for the friends or watching movies in the evening Hospital for over two weeks, working lived in a room of Oxford's John Radcliffe infected with the SARS-CoV-2 virus. He person in the Oxford trial to be willingly In May of 2021, Patel became the first

to create a thought experiment; it's quite another to put philosophy into action. Endless debates rage on Twitter and most part his friends and colleagues were supportive. Many medical ethicists, however, were not. It's one thing

BY THE END OF 2020, when Patel any of Singer's essays.) "It was just this incredibly positive over 1.7 million COVID deaths had been to participate in the Oxford challenge trial added his name to a list of people willing team of other effective altruists started 1Day Sooner. When COVID-19 arrived in New York, Morrison and a people to donate healthy kidneys to those who need them. solve the national kidney shortage by making it easier for that high, he founded Waitlist Zero, a nonprofit that tries to experience for me," he says. In an effort to keep chasing ideas. (Though he notes he's not sure if he's actually read THE AGAINST MALARIA Effective

moral obligation. to help people in dire need isn't charity, he argued; it's a

coalesced under the umbrella term "effective altruism." of those solutions on the real world. These organizations to find and implement solutions, and to study the impact launched an online community to identify global problems their incomes to charity organizations. Two years later, they who in 2009 pledged to give away a significant portion of philosophy grad students Toby Ord and William MacAskill the effectiveness of different charities. Singer also inspired the two started Give Well, an organization that evaluates analysts Holden Karnofsky and Elie Hassenfeld. In 2007, Decades later, Singer's work inspired former hedge-fund

utilitarian idea that the good effects of an action can be Tallinn and even Elon Musk among tech billionaires like Skype founding engineer Jaan principles. The philosophy has gone on to become popular tanks and causes, while tweeting regularly about its have become key figures, donating millions to EA think possible with their money. Since then, Tuna and Moskovitz using the organization's analyses to make the biggest impact their lifetimes. The couple partnered with GiveWell in 2011, decided to give away the majority of their fortune within founders of Facebook and Asana, and his wife Cari Tuna, tively small community until Dustin Moskovitz, one of the quantified and compared. The movement remained a rela-In a nutshell, EA blends Singer's call to action with the

one of his kidneys to a stranger, a move inspired by Singer's community and philosophy incentivize him to be the best unfulfilled corporate lawyer when he decided to donate person he can be. In 2011, Morrison was a successful but For 1Day Sooner co-founder Josh Morrison, the EA

altruism

premise that is based on the

that will do the most good for energy in ways money and the most people use their time, people should





DOCTORS GAVE PLACEBOS to Black men with syphilis (and told them they were being treated) while denying them medications like penicillin as part of the Tuskegee Syphilis Study, which ran from 1932 to 1972.

are often somewhat surprising. most? Which solutions merit time or money? The answers the Effective Altruism Forum. What problems matter the in online blogs and discussion groups like LessWrong and

than donating to your local food bank. better use of said buck, effective altruists would argue make a difference. More bang for your buck — and thus a 150,000 deaths. At \$2 per net, that's a pretty good return distributing 200 million nets and estimates it's prevented tributes anti-malaria nets in Africa. The nonprofit reports is the Against Malaria Foundation, an organization that dis For example, one of EAs most common donation targets and, in theory, it means that anyone can

asking people to risk their health and safety. to donate money. EA had moved out of the realm of theory and into a very real situation in which 1Day Sooner was But the Oxford trial wasn't an online debate about where

its progression. Later, in 1946, the U.S. infected over 5,000 the disease and denied them treatment in order to study which they enlisted Black men who had already contracted government began the infamous Tuskegee Syphilis Study, in science and the betterment of humanity. In 1932, the U.S. Researchers have committed many abuses in the name of including a long history of medical testing on humans. trial requires balancing a complex series of variables, Deciding when it's appropriate to run a human challenge

> unsuspecting and unconsenting people in Guatemala with syphilis and other sexually transmitted diseases. And begin continue until the 1970s. disabled children with hepatitis. Those experiments would to studies that deliberately infected their developmentally School on Staten Island coerced parents into consenting ning in the mid-1950s, doctors at the Willowbrook State

communities like the homeless, children and the elderly. boards to evaluate when it's appropriate to use human without placing additional burdens on already vulnerable be representative of the population scientists want to treat ticipants from dying. Beyond that, the participants need to that it won't have any serious, long-term complications; and well designed; the disease has to be self-limiting, meaning another way to gather their desired data; the study must be justify a challenge trial, researchers must show there isn't subjects, and the U.K. has similar rules. The requirements Research Act in 1974, which requires institutional review here has to be some kind of rescue therapy to keep parare numerous and notably different from EA's criteria. To To combat these offenses, Congress passed the National

repeating history. Those previous, egregious mistakes were instrumental in creating the current research structure. have been adopted since the horrors of Willowbrook and Tuskegee, among others, American ethicists remain wary of Although many laws — both in the U.S. and abroad —

> paternalistic, Sulmasy says those protections are crucial. While idealists like Morrison might call the system

> > op-eds in scientific journals, drafting policy recommenda

studying them in highly controlled hospital settings. But and serious infection by carefully vetting participants and and that researchers could manage the risks of long COVID Oxford COVID-19 trials would reveal new information committee of 18 experienced members decided that the about," says Jeffrey Kahn, director of the Johns Hopkins that good people of goodwill come to different conclusions ot human challenge experiments on a case-by-case basis Berman Institute of Bioethics. In the U.K., an ethics review MOST OF THE TIME, medical ethicists debate the merits and they don't always agree. "It's going to be a calculus

safer and more ethical to run. And yet, ironically, SARs-CoV-2 trial. But could someone have died? I think long COVID. "It's rolling dice," Kahn says. "That's crazy.' Remdesivir, Sulmasy believes these trials would be much mistaken," he says. Now, with treatments like Paxlovid and the answer is yes. And anybody who denies that is sadly Sulmasy agrees. "It's true that nobody died in the initial

dangerous and unnecessary. There was no rescue therapy Kahn and others believe that in 2021, the Oxford trials were

and no way to predict whether participants would develop

it's appropriate to give to volunteers. make a good judgment about whether enough about an unknown disease to trials at all. And scientists don't know serious disease may not merit the may be unethical. Meanwhile, a lessinto a paradox: Though there's a lot to the need is no longer as crucial. a deadly disease, actually doing so learn from infecting participants with Challenge trials often end up running

experience, but he hasn't jumped at the chance to enroll in admits they still make him nervous. He doesn't regret the test and a less-crippling aversion to needles — though he out of John Radcliffe Hospital with a negative PCR and throat swabs, 17 days in a hospital oom and eight blood tests later; Patel walked

Seventy-one vitals checks, 31 nose

Meanwhile, 1 Day Sooner continues to push on, writing

among experts, then you should default tuberculosis, hepatitis C and COVID-19, clear: Millions of people die of diseases like he says. For him, the moral accounting is to the people who are directly affected," trials pose. "When there's disagreement whether to take on the risks challenge to argue that informed participants should be able to choose national pandemic preparedness plan. Morrison continues and lobbying to make challenge trials part of the U.S.'s tions, enrolling volunteers for a hepatitis C challenge trial, often end up trials running into Challenge

trials and vaccine research involve immense trial isn't just a personal decision. Human guide them. But signing up for a challenge selves freely with good data and evidence to that people can make decisions about them trials isn't a simple choice. 1Day Sooner and funding from governments, foundations EA more broadly operate on the assumption and research centers. That funding is a Nonetheless, participating in challenge kind of implicit endorsement,

a deadly disease

participants with

may be unethical actually doing so a lot to learn a paradox:

Though there's

from infecting

and challenge trials could make a difference.

and it adds a layer of weight and pressure on research participants: Do this for the good of the country, the economy and humanity.

to dive in either. When governments institutional pressure pushing people them. On the other hand, there's no that Peter Singer used five decades keep people from rushing in to save Governments don't set up fences to ago: Imagine a child is drowning Kahn uses the same comparison

them to lay down on the sword. Kahn says, but that doesn't mean institutions should ask "People want to sacrifice themselves and be called heroic," the payoff is big enough to even merit the request good of others, there needs to a consensus that

start asking people to risk their lives for the

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The Dark Side of Effective Altruism

privileged white men, a homogeneity that limits how neglecting to address the structural ills that cause movement tends to focus on single actions while the philosophy understands effectiveness. inequity in the first place. It's also dominated by Effective altruism has plenty of discontents. The

value free, that we're all paper cut-outs of the same "The assumption is that effective altruism can be

themselves and their while failing to place they're acting objectively altruists proclaim that In other words, effective of critical essays on EA. Harm It Does, a collection The Good It Promises, the Carol Adams, a co-editor of person, but we're not," says

right now. problems affecting people than paying attention to far in the future, rather though presented as small possibility of changes fallible, often fixating on the neutral and moral, are And EA's conclusions privilege in a wider context

or the hubris that they know about how change happens imagination in thinking me more: the lack of don't know what offends always easy to quantify. "I whose impacts are not community organizing, to recognize the value of Critics say EA also fails

school. as a small protest at her whose advocacy started environmental movement the answer to changing inspire a global youth activist who helped Thunberg, the Swedish the world," says Adams Take, for example, Greta

Fried. The now-disgraced Then there's Sam Bankman harassment and coercion that allows for sexual a toxic culture within EA behavior. Women report to excuse members' bad has used the philosophy the way the EA movement Perhaps most troubling

bigger moral ends. - S.H. they were committed on the cryptocurrency tycoon gave way toward (supposedly) immoral actions because became a way to rationalize large-scale fraud. EA while also committing (including 1Day Sooner) millions to EA organizations

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