

antidote //

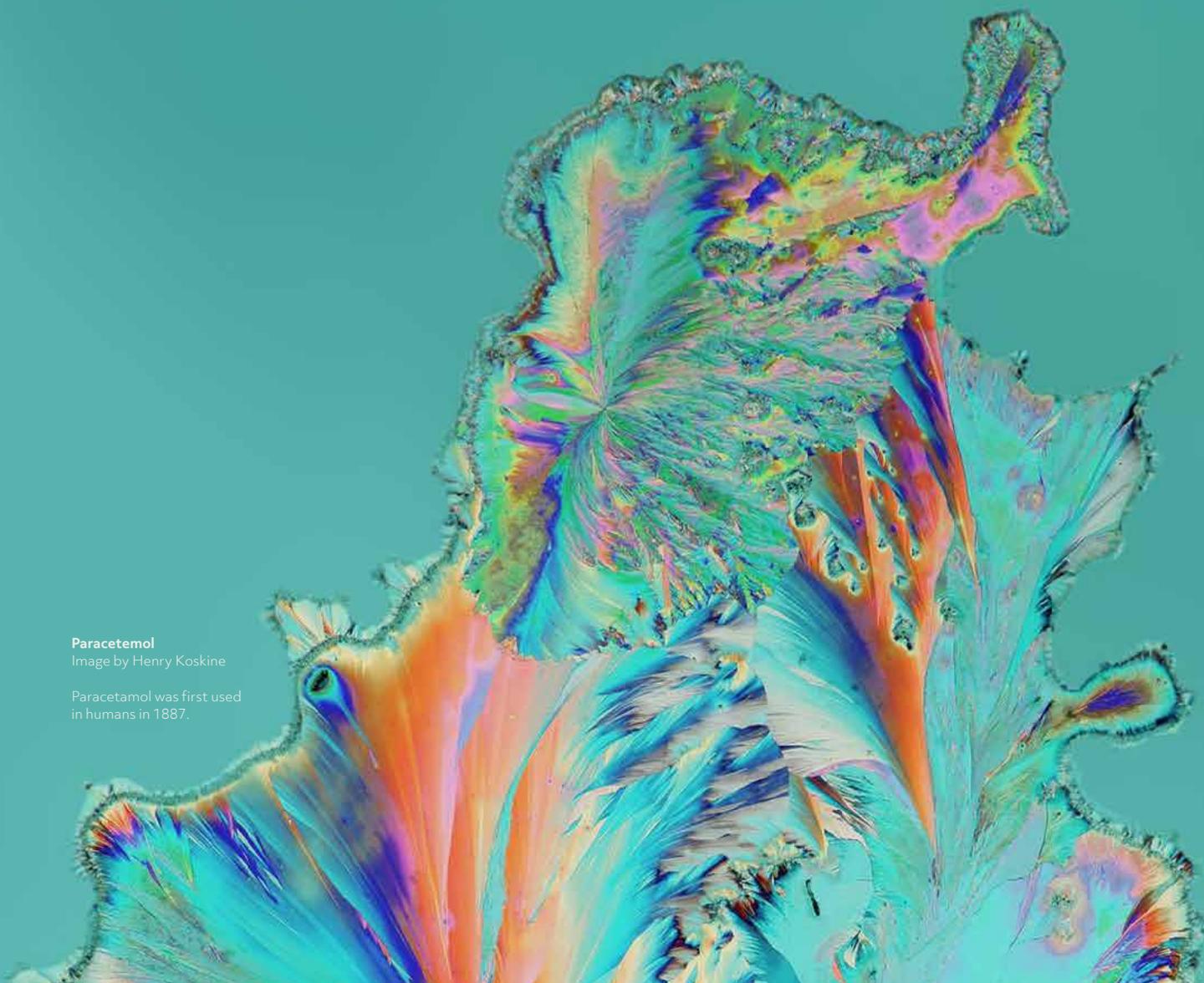
www.antidote.me

Minority Participation in Clinical Trials:

Research Diversity Leads to Better Outcomes for All

Paracetamol
Image by Henry Koskine

Paracetamol was first used
in humans in 1887.



Increasingly, research shows that the best way to tackle a range of challenging diseases varies from person to person. For example, researchers are working toward precision medicine treatments for a range of conditions, from cancer to Parkinson's disease — and we also know that some treatments work better in certain groups of people than in others.

Unfortunately, there's one major barrier to expanding access to these life-changing treatments: A lack of diversity of clinical trial participation.

At first glance, you could conclude that the problem of minority participation in clinical trials has been solved. For all NIH clinical trials combined, the participant population generally matches the makeup of the U.S. But zeroing in on individual conditions tells a different story — one that leads to worse health outcomes for communities of color.

For example, in a review published in PLoS Medicine, researchers found that only 2% of cancer studies and less than 5% of pulmonary studies have included enough minority participants to provide statistically significant information.

Those low rates mean that treatments may not work as well across different genetic backgrounds. For example, the blood thinner Plavix doesn't work in 75% of Pacific Islanders, because their bodies don't produce the enzyme that activates the drug.

2% of cancer studies and less than 5% of pulmonary studies have included enough minority participants to provide statistically significant information.

Even for conditions that disproportionately impact communities of color, current treatments aren't as effective for them. Asthma is more common in African Americans and Puerto Ricans, but the most commonly prescribed medication for asthma also doesn't work as well in these populations as it does in white patients. The most commonly prescribed treatment for lupus also doesn't work as well in black and Latino patients, though the condition is two to three times more common in women of color.

That's why research professionals and patient advocates are working to improve representation and drive better treatments for all patients. From identifying barriers to participation to creating programs to better connect with participants, clinical research is moving toward a more inclusive – and more effective – approach to trials.

“ We want to acknowledge the historical harm, especially in communities of color and underserved communities, of what has happened with clinical trials. We want to share that and acknowledge it.”

Regina Greer-Smith, Founder, S.T.A.R. Initiative



One well-known barrier to minority participation in clinical trials is an understandable lack of trust. [The Tuskegee Institute syphilis study](#) in particular has contributed to a concern that minority trial participants may be taken advantage of in clinical research. The study recruited 600 black men to participate in a trial researching syphilis treatments. The researchers lied about the goal of the study, saying they were being treated for “bad blood,” and did not offer participants syphilis treatment even once penicillin became widely recommended. The study ran for 40 years.

“We want to acknowledge the historical harm, especially in communities of color and underserved communities, of what has happened with clinical trials. We want to share that and acknowledge it,” Regina Greer-Smith, founder of the S.T.A.R. Initiative, said. “We want to let them know that there are steps and protocols and laws in place so that cannot happen, and how important it is for them to participate in clinical trials.”

The S.T.A.R. Initiative aims to engage researchers who are interested in connecting with communities on a deeper level around clinical trial participation. Then, the researchers will share information about clinical trials in language that patients can better connect with.

For Greer-Smith, it all comes down to forging stronger bonds between researchers and the communities they aim to work with. She’s been involved in raising clinical trial awareness for a few years now, and anecdotally, she’s seen an increase in interest, too.

“People don’t throw me out of rooms now when I talk about clinical trials,” she said with a laugh. “People want to know and they want to share. They’re starting to understand and they see that there are benefits to clinical trials.”

The next step is for patients to gain better access to providers with knowledge of clinical trials. One of the easiest ways for patients to learn about an appropriate trial is at the doctor's office. But

patient advocates have found that diverse communities typically have less access to specialists and other physicians who are informed of clinical trial opportunities.

Around half of both minority and white respondents cited "lack of information" as the main reason they don't participate, in a [survey from Research!America](#).

"Minorities are underrepresented in clinical trials because of substantial patient- and provider-side barriers," said Stacey Boyd,

MS, Senior Communications Manager, Collaborative Initiatives at the American College of Rheumatology (ACR).

The ACR runs several programs that connect rheumatologists with information related to clinical trials to distribute to patients.

In fact, lack of information may be an even stronger force keeping minorities from participating in research than lack of trust.

Around half of both minority and white respondents cited "lack of information" as the main reason they don't participate, in a [survey from Research!America](#).

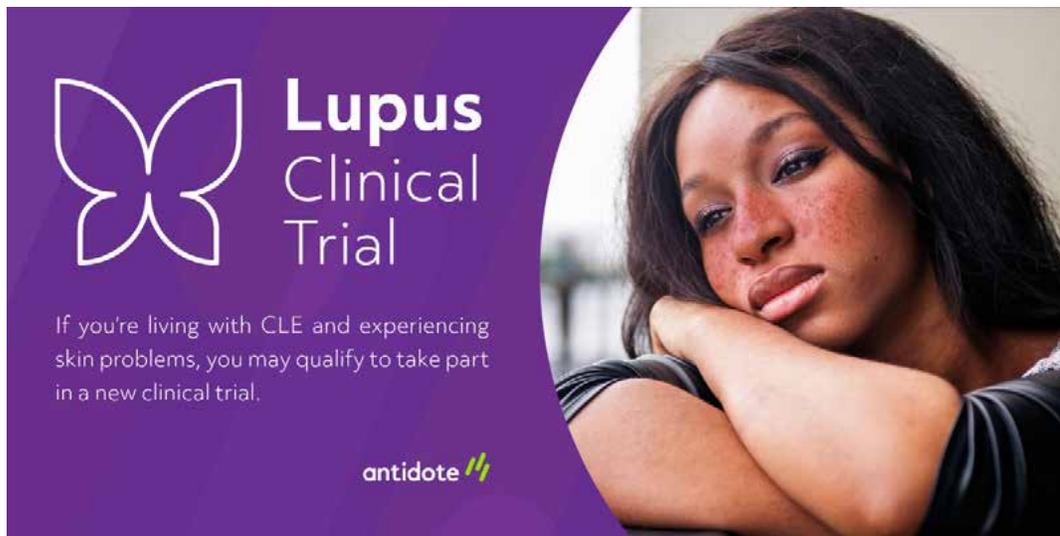
In other words, sometimes the way to increase minority participation in clinical trials is to simply ask.

When a University of Florida research team [surveyed 6,000 residents](#) of five large cities, [91%](#) of Africans Americans surveyed expressed an interest in participating, compared with [85.5%](#) of white respondents. The interest is there – the next step is to invite patients in. That can mean meeting patients where they already are.

“For a diabetes trial seeking minority women participants, I will think of patient, minority, and health professional groups,” said Audrey Sheppard, president of Audrey Sheppard Women’s Health Consulting and former head of the Office of Women’s Health at the FDA. “Who provides care for diabetes patients? It’s not just endocrinologists, but also dieticians, podiatrists, on and on.”

For example, recently when she was seeking adult women of color for a lupus clinical trial, she connected with an organization called Black Nurses Rock to help share trial opportunities with their engaged network over social media and in person.

“Everyone will benefit if a clinical study looks more like the public,” she said. “Getting the word out is everyone’s job.”



An example of the Lupus clinical trial ads run by Black Nurses Rock

Diversity makes research better

Nonprofit organizations are also getting involved in identifying knowledge gaps in research that's already been conducted. The Multiple Sclerosis Association of America (MSAA), for example, analyzed data from six randomized, placebo-controlled studies to measure differences in disease outcomes for white, black, Asian, and Hispanic MS patients. But because the vast majority of participants were white, the data was too difficult to analyze.

Since then, the MSAA has launched several projects to help improve minority participation in MS clinical trials. Amanda Montague, Ed.M., Vice President of Education & Healthcare Relations at MSAA, has noticed a change in how the MS community talks about trial participation just in the last few years.

"I think the MS community is more sensitive to the need to actively involve underserved and minority patient populations in clinical studies, and are working at doing a better job of educating minority patient populations about the importance of their involvement in clinical trials," she said.

In all, these efforts seem to be working. Between 2010 and 2014, for example, the number of African American trial participants increased from 10% to 23%. Studies suggest that trust toward clinical research has improved from the perspective of the African American community. A survey conducted by Research!America in 2017 found that the number of respondents who reported "lack of trust" as a reason to not participate dropped by 15 percentage points in minority populations since 2013.

Between 2010 and 2014 the number of African American trial participants increased from 10% to 23%

And recent studies specifically related to differences in health outcomes among different populations have already yielded important results.

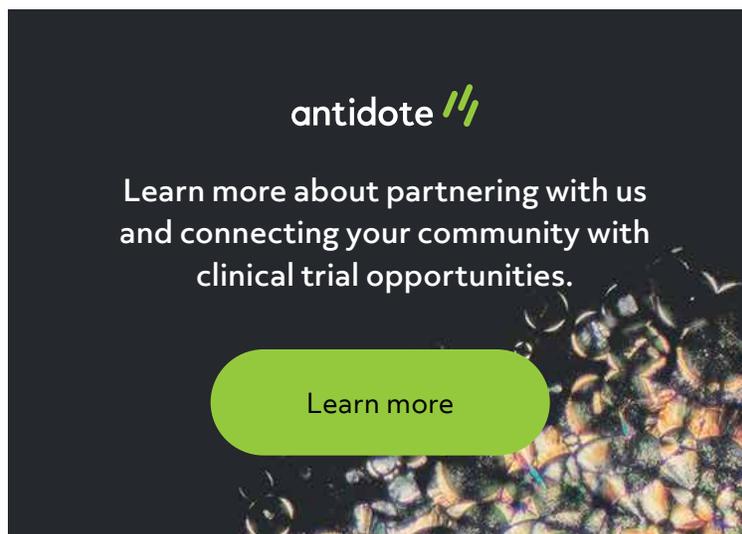
In March, researchers found a gene that could contribute to heart failure rates among African Americans. Though African American patients are nearly twice as likely as white patients to die from heart disease, it was the first time black patients were specifically surveyed about heart disease.

“ Our chemical makeup, our heritage is just as important to learn about as anyone else’s when we examine who we are as a people and how it plays a role in medical science and the diseases we are diagnosed with.”

Shaina Smith, Director of State Advocacy & Alliance Development, U.S. Pain Foundation

The more minority participation there is in clinical trials, the closer we’ll get to better treatments for everyone. Shaina Smith, Director of State Advocacy & Alliance Development at the U.S. Pain Foundation, is involved in patient engagement and empowerment work. As a Puerto Rican woman, she also feels personally invested in encouraging people of color to take part in research.

“We need to show our communities that research is necessary to partake in so that our children have hope that there will be a cure or a promising therapy that can help their condition,” Smith said. “Our chemical makeup, our heritage is just as important to learn about as anyone else’s when we examine who we are as a people and how it plays a role in medical science and the diseases we are diagnosed with.”



antidote 

Learn more about partnering with us
and connecting your community with
clinical trial opportunities.

Learn more