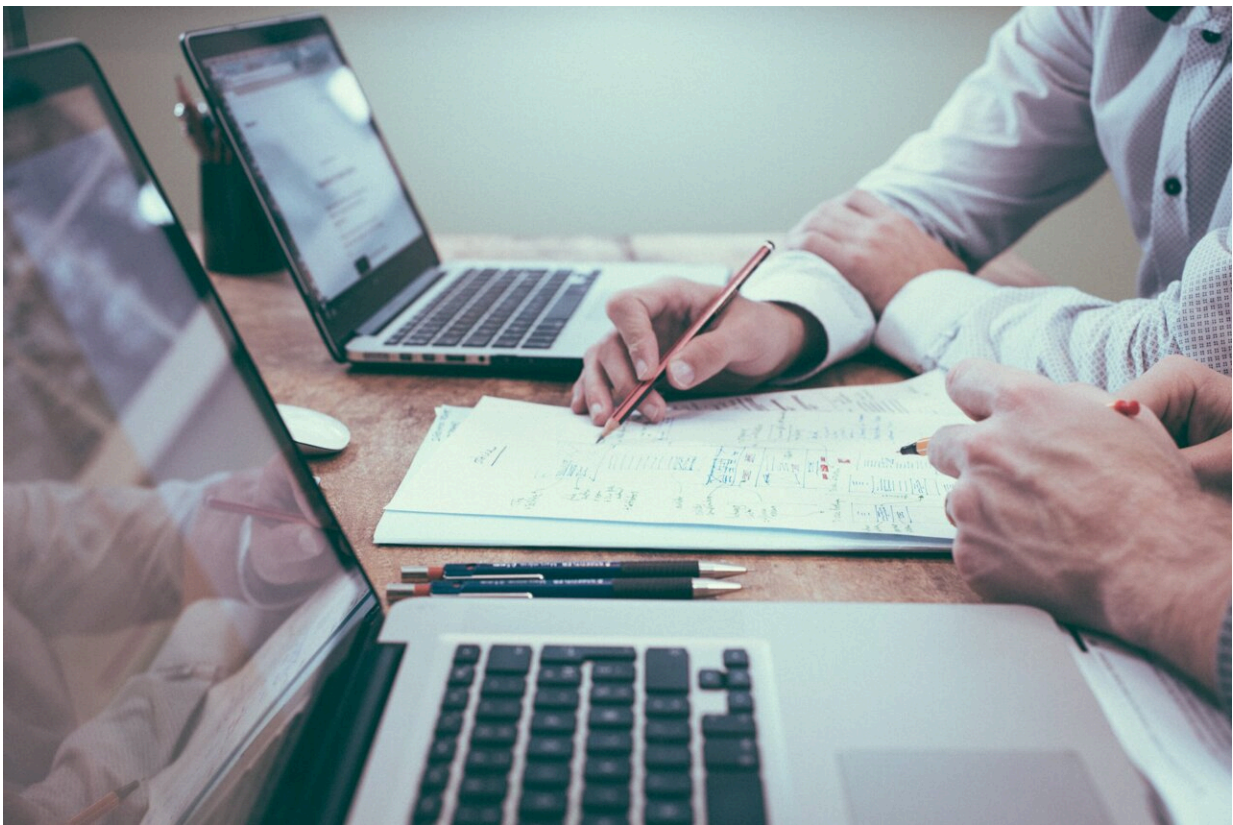


Marketing study of sickle cell patients looks at effects of racism on the adoption of innovative therapies

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A recent study by University of Illinois Chicago researchers in the College of Business Administration analyzed how the experiences of

racism and discrimination in health care significantly affect the adoption of innovative medical technology like gene therapies and the gene editing tool CRISPR.

The study, "In the Back of the Bus: Racialized High-Risk Consumption and Sickle Cell Disease," published in the *Journal of the Association of Consumer Research*, focused on consumers impacted by [sickle cell disease](#), which disproportionately affects the Black community with 100,000 Black patients in the United States alone.

Lez Trujillo Torres, assistant professor of marketing and Benét DeBerry-Spence, professor and head of the marketing department, focused on how Black patients deliberate health care risks and how they evaluate innovative medical technologies. They focused on more than 3,200 archival data materials including governmental sources such as the Centers for Disease Control and Prevention, health institutions, news media, and social media.

The researchers found that inequalities in the marketplace can be so disruptive that patients and their families are willing to forgo planned treatments and even health innovations that may result in a cure. On the other hand, some patients can be attracted to innovations because they are trying to escape experiences of racism and discrimination but the path to them is plagued with obstacles.

They noted that when Black patients deliberate risk related to health treatments, it is more than their individual experiences that come into play. These patients weigh the racism and discrimination they have experienced individually when seeking and receiving [health care services](#), as well as the collective experiences of Black sickle cell patients, said DeBerry-Spence.

This perspective is informed by patients' awareness of the legacy of

experimentation and exploitation of Blacks in [genetic research](#), such as the unauthorized harvesting of cells from Henrietta Lacks, an African American who died of ovarian cancer. Their perspectives are also linked to the effects of present day systemic racism and the resulting inequities in clinical care and health outcomes.

It is a combination of what is good for the individual and what has been the history behind a racial group's experiences with health care. This means that a necessary trip to the [emergency room](#) may be delayed as Black patients recall recent and past instances of discrimination regarding health care. Some [community members](#) warn others not to disclose health histories and to even dress differently to avoid negative stereotypes from [health care](#) providers.

"These patients try to mitigate the risks that might come so that they are not denied basic care and that health providers believe them when they go for pain medication for instance or go to the ER," said Trujillo Torres.

Several takeaways related to the successful adoption of innovative technologies emerge from this research. Patient experiences with basic medical care are crucial in risk assessments of gene therapies and other medical technologies. This means, for example, that negative experiences during ER visits factor into patient assessments of gene editing tools like CRISPR.

Institutions and medical professionals promoting and introducing innovative therapies, then, must consider the role they play in creating distrust. Scientists and the broader medical community should acknowledge that Black patients have a complex risk deliberation that includes personal and collective aspects.

More information: Lez Trujillo-Torres et al, In the Back of the Bus:

Racialized High-Risk Consumption and Sickle Cell Disease, *Journal of the Association for Consumer Research* (2022). [DOI: 10.1086/722684](https://doi.org/10.1086/722684)

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