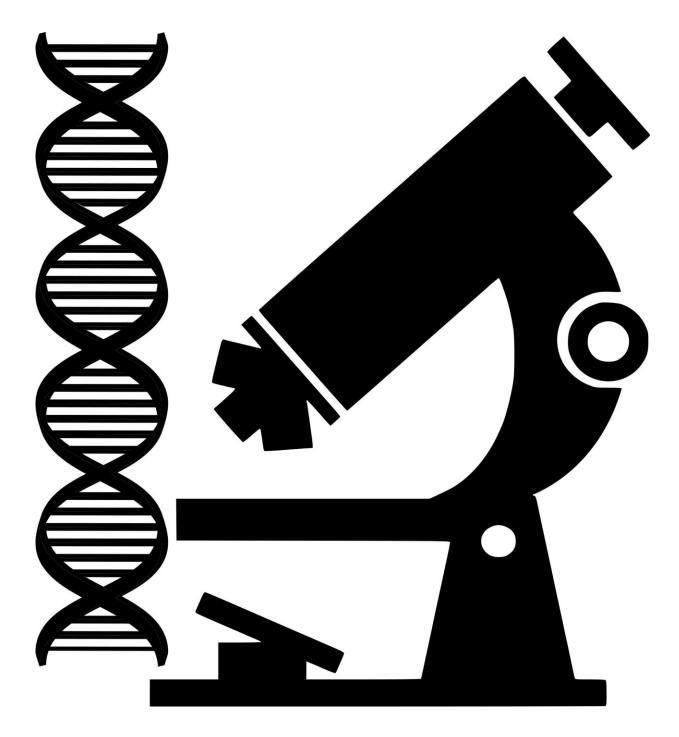


## Black people half as likely to be evaluated for genetic testing as white people, finds study

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Genetic testing has become a more common way to diagnose and manage many neurologic conditions including dementia, Parkinson's



disease and epilepsy, but a new study has found not everyone may have the same level of access to these tests.

Black people were half as likely as white people to be evaluated for <u>genetic testing</u>, according to a study <u>published</u> in *Neurology*.

"Genetic testing is crucial for identifying <u>neurologic conditions</u> and has potential to impact treatment and management of symptoms," said study author Colin A. Ellis, MD, of the University of Pennsylvania in Philadelphia and member of the American Academy of Neurology. "This testing is something that everyone, regardless of race or <u>ethnic</u> <u>background</u>, can benefit from. However, our study found that being evaluated for this testing was unequal among Black people. This indicates disparities in the accessibility of this potentially life-changing process."

Genetic testing looks at a person's DNA for variations in genes associated with a disease. This can be helpful for diagnosis and management of a disease, as well as family planning.

Researchers looked at 128,440 people in the Philadelphia area who visited neurology clinics during a seven-year time frame. Of those, 2,540 people were evaluated to receive genetic testing.

Researchers looked at three steps of the genetic testing process: attending an evaluation, completing genetic testing and receiving a diagnosis. They looked at people with seven neurologic diseases: ALS, ataxia, dementia, epilepsy, myopathy, neuropathy and Parkinson's disease.

Among all participants, 73% were white and 20% were Black. However, among participants evaluated for genetic testing, 81% were white and 11% were Black.



After adjusting for ethnicity, <u>socioeconomic status</u>, and insurance status, Black people were 51% less likely than white people to be evaluated for genetic testing.

Among those who were evaluated for genetic testing, Black people had more neurology office visits before their evaluation, with 16 visits, than white people, with 14 visits. Ellis noted this may suggest a bias in how people are referred to this testing.

"While we found disparities in receiving a genetic evaluation, once people were evaluated, everyone benefited similarly from genetic testing when prescribed," Ellis said. "More work is needed to address these <u>health care disparities</u>, such as providing culturally sensitive genetic counseling services in multiple languages. Policies that focus on making genetic testing more affordable as well as expanding <u>insurance coverage</u> could also reduce disparities."

A limitation of the study was the small number of participants of other races and ethnicities. Also, the study was conducted at one <u>medical</u> <u>center</u>, so the results may not apply to other centers or settings.

**More information:** Aaron Baldwin et al, Disparities in Genetic Testing for Neurologic Disorders, *Neurology* (2024). <u>DOI:</u> <u>10.1212/WNL.00000000209161</u>

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