

Exploring Racial/Ethnic Differences in the Chiari Experience

The All of Us research program is an ambitious project administered by the National Institutes of Health which collects electronic health records, surveys, biological samples, and standard assessments from US residents and makes the information freely available for research. As of 2022 the database contained information on over 400,000 people.

Recently, a group of researchers used the database to explore the impact of race/ethnicity on the Chiari experience. Specifically, they identified 996 Chiari adults who had self-reported their race/ethnicity and then compared their health status, understanding of patient literature, and access to healthcare. The patient group was 57% non-Hispanic white, 23% non-Hispanic Black, and 20% Hispanic/Latino. Demographically, there were significant differences between the groups in terms of education, employment, income, health insurance, and marital status. For example, over half of the Black and Hispanic groups were on Medicaid compared to 23% of the white group. Similarly, home ownership percentage for both the Black and Hispanic groups was less than half of the white group.

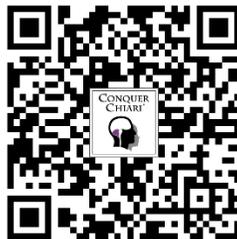
In terms of health status, the Hispanic group reported the highest pain levels, with 11% reporting a pain level of 10 out of 10 in the past seven days. This compared to 7% of the Black group and 4% of the white group. While there was not a significant difference between the groups in terms of fatigue, the Hispanic group had nearly double the percentage of people who reported they could not engage at all in daily activities. Similarly, the Hispanic group rated themselves significantly lower than the other groups on both physical and mental health.

One of the most striking findings was that more than half of the Hispanic group reported they had difficulty in understanding patient information and that they needed assistance in this regard. It is worth noting that Conquer Chiari recently started a project to provide our Chiari Academy videos in Spanish (as well as English). The first video, a Spanish version of Understanding Chiari is now available on our website.

Chiari is difficult to deal with for anyone but this data shows that some patient groups have additional issues they must overcome.

Source: Ghanekar SD, Serrato P, Hansen J, et al. Racial/Ethnic Disparities in Perception of Health Status and Literacy in Adult Patients With Chiari Malformation Type I: Insights From the All of Us Research Program. *Neurosurgery*. Published online February 6, 2026. doi:10.1227/neu.0000000000003939

Please consider a \$10 donation as Conquer Chiari's educational material is free to read, but not free to produce:



<https://www.conquerchiari.org/donate>

Conquer Chiari's research updates highlight and summarize interesting publications from the medical literature while providing background and context. The summaries do contain some medical terminology and assume a general understanding of Chiari. Introductory information and many more research articles can be found in the [Conquer Chiari Library](#).