

Lack of trust less of a barrier to clinical trial participation, say minority populations

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Significantly fewer African-Americans, Hispanics, Asians and non-Hispanic whites say 'lack of trust' is a reason why individuals do not participate in clinical trials, indicating a more favorable perception of this research. In a recent public opinion [survey](#) commissioned by Research!America, the percentage of respondents citing 'lack of trust' as a reason declined by as much as 15% among minority groups and the population overall, compared to the results of a 2013 survey—50% of African-Americans (11% decrease), 45% of Asians (6% decrease), 43% of Hispanics (9% decrease) and 39% of non-Hispanic whites (15% decrease).

When asked if they or someone in their family has ever participated in a clinical trial, the percentage of African-Americans who said yes increased strikingly from 15% to 22%. Among other groups, percentages increased slightly or remained the same. Although less than a quarter of any group said yes, strong majorities said they would likely participate in a clinical trial if their doctor found and recommended one—non-Hispanic whites (85%), Hispanics (81%), African-Americans (74%) and Asians (73%).

"As more information about [clinical trials](#) is shared broadly, especially by physicians, we should continue to see an uptick in the number of Americans across all groups who recognize the value of clinical trials," said Mary Woolley, president and CEO, Research!America. "The next challenge is to ensure that all segments of the population have access to enrollment opportunities in order to boost participation and advance

medical progress."

About half of minority group respondents as well as non-Hispanic whites cite 'lack of information' as a reason individuals do not participate in clinical trials, largely unchanged from the 2013 survey. When asked which organization or group has the greatest responsibility in educating the public about clinical trials, the majority of respondents said doctors and [health care](#) providers.

A significant percentage of minority group respondents and non-Hispanic whites say doctors and [health care providers](#) are a reliable source for clinical trial information, but only 27% of Hispanics, 25% of Asians, 24% of African-Americans, and even fewer non-Hispanic whites (15%), say their doctor or other [health](#) care professional has ever talked to them about [medical research](#). Notably, the results indicate a higher percentage of [minority groups](#) say they are having discussions about medical research with health care providers than non-Hispanic whites. But all groups agree that [health care professionals](#) should discuss clinical trials with patients diagnosed with a disease as part of their standard of care - 89% of Hispanics, 88% of non-Hispanic whites, 86% of Asians and 79% of African-Americans.

"Medical products are safer and more effective for everyone when clinical trials include diverse populations," said Karen Noonan, vice president of global regulatory policy of the Association of Clinical Research Organizations (ACRO). "ACRO welcomes these valuable data from the Research!America survey, which reinforce Congress' direction to the Food and Drug Administration to evaluate and address the inclusion of minority and other demographic subgroups in clinical trials."

As seen in the overall population, a strong majority of minority group respondents say they would be willing to share personal health

information so researchers can better understand diseases and develop new ways to prevent, treat and cure them, improve patient care, advance medical research and so public health officials can better track disease and disability and the causes. And most say they are likely to use technology to share personal health data—75% of Hispanics, 70% of non-Hispanic whites, 69% of African-Americans and 68% of Asians. In addition, minority groups say they would prefer to have clinical trial information/data/results delivered through their phone - 58% of Hispanics, 53% of African-Americans and 50% of Asians, compared to 39% of non-Hispanic whites. About half of all groups say they have heard about clinical trials from the internet.

Altruism has remained a significant motivating factor for clinical trial participation, especially among minority groups. More than half of African-Americans (61%) and Hispanics (56%) say the opportunity to improve the health of others is a very important reason to take part in a clinical trial, compared to 50% of non-Hispanic whites and 46% of Asians, similar to 2013 findings.

In addition, a majority say understanding risks and benefits, and the competence and reputation of the people or institution conducting the research, and having an expert guide them through the clinical trials process are very important factors in their decision to participate as a volunteer in a clinical trial.

Significantly, a lack of awareness about clinical trial enrollment is reflected in responses among all groups. When asked if patients are sometimes included in clinical trials without being told when they are receiving medical treatment, percentages increased slightly among all groups from 2013. "Health care professionals must routinely inform patients that there is no enrollment without consent," Woolley noted. "Unless this misperception is addressed, it could undercut advances in perceptions of trust in clinical trial participation."

Among other findings:

- Many respondents agree that clinical trial participation should be a routine health behavior, whether you are healthy or ill, similar to getting an annual checkup with your health care provider—56% of Hispanics, 51% of Asians and 48% of African-Americans, compared to 38% of non-Hispanic whites.
- Plurality say they greatly admire individuals who volunteer for clinical [trials](#)—52% of Hispanics (10% increase from 2013), 48% of non-Hispanic whites (13% increase), 47% of African-Americans (1% increase) and 45% of Asians (2% increase).
- A higher percentage of minorities say we are not making enough progress in medical research compared to 2013 - 46% of African-Americans (13% increase), 40% of Hispanics (11% increase) and 37% of Asians (7% increase). The percentage dropped slightly among non-Hispanic whites.
- When asked if the health care services they receive are based on the best and most recent research available, the percentage saying "no" climbed significantly across the board compared to 2013 - 46% of African-Americans (18% increase), 45% of Hispanics (14% increase), 40% of non-Hispanic whites (7% increase) and 38% of Asians (8% increase).

The nationwide survey was conducted by Zogby Analytics for Research!America and the Association of Clinical Research Organizations in July 2017. The margin of error ranges +/- 3.1 to +/- 5.6 percentage points. To view the survey, [click here](#).

Provided by Research!America

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