

Subject Recruitment 2011

MMG strategic initiative to address disparities in clinical research participation among Hispanic and Latino communities.

Todos Juntos por la Salud

John Benbrook

Hispanics and Latinos are the second largest population group within the United States, making up 16% of the total US population. The US Hispanic population is expected to triple by 2050. Second generation Hispanics and Latinos—those born in the United States with at least one foreign born parent, make up the fastest growing segment. With an average age of 27, the future of the nation's healthcare costs will be closely tied to the health and health behaviors of US Hispanic and Latino populations as they age. Diseases such as cancer, depression, and HIV are becoming more prevalent in this demographic than in non-Hispanic/Latino communities. When cancer is diagnosed in Hispanics and Latinos, it is at a more advanced stage of the disease because this group often delays seeking a physician's care. Latinas under the age of 18 have the highest rate of suicide (11.5%) in comparison to non-Latina whites. Latino youth have more anxiety, depression, and drug abuse than non-Hispanic whites.

The impact of healthcare costs resulting from non treatment or uncontrolled disease in this group is already high in the United States. New medications play a critical role in reducing the long-term costs of care in undertreated diseases. Also, because certain medications metabolize differently in people of Hispanic/Latino heritage, healthcare providers need more data in Hispanic and Latino patients to better inform their treatment decisions and increase their confidence in prescribing therapies. Unfortunately, the participation rate of Hispanics/Latinos in US clinical research is only about 3%. The research community's ability to address this discrepancy and the course of medical research in this group today will affect the health and healthcare system of the United States for several generations to come. Steps need to be taken now to achieve greater Hispanic and Latino representation in medical research.

Not a new problem

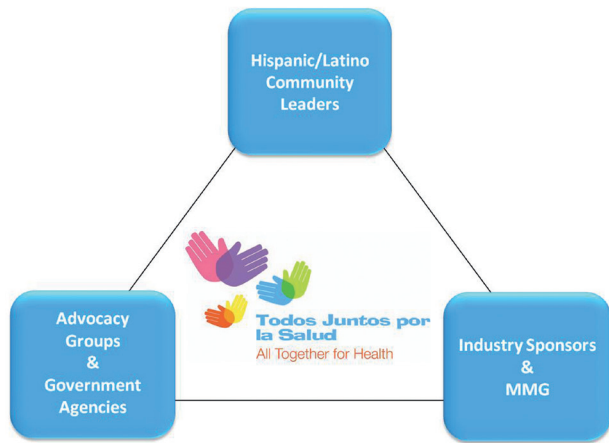
National Institutes of Health (NIH) has led the way to be more inclusive of women and minorities in clinical research. The NIH issued a guideline, "The Inclusion of Women and Minorities as Subjects in Clinical Research," to ensure all NIH-funded clinical research is performed in a manner sufficient to elicit information about individuals of both genders and diverse racial and ethnic groups, and to examine differential effects on such groups. An example of how this has driven efforts is the NIH-funded PACT program, in which NIH and MMG teams have partnered to support patients one-on-one in Washington, DC-area communities to bring study participation information and opportunities to the underserved. There has also been some limited success in engaging Hispanics and Latinos in clinical trials through efforts made by the National Cancer Institute and other institutions.

A new initiative

Driven by concern that clinical trial participation among Hispanics and Latinos is disproportionately low compared to their percentage of the United States population, MMG has partnered with Hispanic and Latino healthcare community leaders to form Todos Juntos por la Salud (www.juntosforhelath.com). Todos Juntos is looking to significantly reshape the landscape of clinical research to be more inclusive of multi-cultural subgroups in the United States. The first phase of the program is aimed at better understanding the barriers to research faced by Hispanics and Latinos, and to identify strategies for overcoming them. Todos Juntos has brought together three major stakeholder groups, all contributing toward greater Hispanic and Latino representation in medical research.

The first stakeholder group is leaders of the US Hispanic and Latino communities, which are contributing vital cultural competency education. This group's involvement is

**Todos Juntos por la Salud
Strategic Initiative**



Source: MMG

Figure 1. A presentation of what is expected from Todos Juntos por la Salud—a cross-section of partners all contributing to achieve greater Hispanic and Latino representation in medical research.

essential to the initiative’s ability to effectively engage both patients and healthcare providers in the Hispanic and Latino communities, and in raising their awareness and understanding of clinical research.

The second arm of Todos Juntos is advocacy groups and government agencies like NIH, the American Heart Association, the National Latina Network, the National Association of Hispanic Nurses, and the National Hispanic Medical Association. Each of these organizations is changing lives in local communities through education, awareness, and research. Their participation in Todos Juntos is a natural extension of their missions.

The third stakeholder area brings study sponsors and clinical trial support providers like MMG into the picture. In addition to funding the initiative, these groups will translate Todos Juntos learnings into changes in study design and execution that are needed to increase Hispanic and Latino participation in clinical trials.

Launching Todos Juntos

In February, MMG hosted a forum in Dallas, TX, as an inaugural event for the Todos Juntos initiative. The forum brought

together Hispanic and Latino community leaders and health industry stakeholders to discuss the root causes behind the disparities in medical research participation, what needs to occur to increase engagement, and how groups can collaborate to achieve these goals. Morphotek, Amgen, and Zocolo, supported the event, and Elena V. Rios, MD, MSPH, President and CEO of the NHMA (National Hispanic Medical Association) moderated. NHMA is an advocacy group representing more than 45,000 Hispanic physicians across the United States. Rios noted:

When we see Hispanic leadership involved in clinical research, we will see real change. The NHMA, along with other advocacy groups such as the National Association of Hispanic Nurses, Hispanic American Colleges and Universities, and the National Resource Center for Hispanic Mental Health, are committed to driving strategic initiatives through this forum that increase Hispanic and Latino representation in medical research.

A repeating theme in the discussions was the need for the research community to increase its cultural competency. A component of this effort needs to be a greater investment in face-to-face communication. While the learnings that come from these efforts will be important at the individual site level, ideally they will impact the way study sponsors craft protocols and informed consents. Specifically, there needs to be acknowledgment of the importance of family in navigating healthcare choices, and particularly in clinical trial participation decisions. Leaders of the Hispanic and Latino communities advised that this would not only improve clinical research acceptance in their cultures, but likely improve understanding and retention of patients from other cultures as well. On a broader plane, Hispanics and Latinos need more appropriate health treatment choices in order to be part of a viable healthcare solution, and ultimately, to help reduce overall costs to the US medical system.

The road ahead

Additional forum outcomes will be shared to raise awareness, promote best practices, and build on the initiative’s momentum. Next steps for the Todos Juntos initiative include a workshop conducted by MMG at the 15th Annual National Hispanic Medical Association Conference designed to help Hispanic/Latino community based physicians get involved in clinical research. The NHMA conference takes place March 17-20, 2011, in Washington, DC (www.nhmamd.org).

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