US genetic health studies fail to accurately represent country's ethnic makeup

The clock is ticking for experts charged with designing a U.S. government programme to collect genetic, physiological and other health data from one million volunteers over the next two decades. The plan for the U.S. $215-million Precision Medicine Initiative (PMI), announced in January, is due in August — a daunting deadline, in part because the effort's priorities include filling racial and socioeconomic gaps left by other long-term studies.

The U.S. National Institutes of Health (NIH), which is leading the PMI, is weighing ambition against a desire to avoid the mistakes that torpedoed its National Children's Study, which would have tracked 100,000 children from birth to adulthood. The agency abandoned that effort in December 2014, after recruiting just 5,700 participants at a cost of U.S. $1.3 billion. It cited overly complex study design and goals.

Clinical trials in the United States have historically relied on enrolling white participants from higher socioeconomic levels, despite the fact that ethnic minorities make up about 40 percent of the country's population. Of the 58,160 lung-disease studies published between 1993 and 2013, for example, less than 5 percent reported the inclusion of participants from minority ethnic groups. The disparity is especially problematic because many diseases are more prevalent among certain ethnic groups, and ethnicity may also influence which therapies are effective, says Esteban Burchard, a physician scientist at the University of California, San Francisco.

The GLP aggregated and excerpted this blog/article to reflect the diversity of news, opinion and analysis. Read full, original post: US tailored-medicine project aims for ethnic balance