Research Nebraska

June 6, 2022

Dear Congressional Representative,

Research Nebraska, Inc strongly supports H.R.5030 & S.2706 in its promotion of diversity within clinical trials. Through inclusive trials, medicine grows to better understand disease and treat all citizens. Increasing variability in demographics is not just the best way, but the only way to conduct a responsible clinical trial. We humbly ask you consider co-sponsoring this bipartisan legislation.

Inclusion within clinical trials is necessary in keeping citizens healthy. Our bodies exhibit symptoms and react to treatments differently based on ethnicity and race; in treating patients, there is no way for clinicians to discount how these differences will affect a patient's outcome. When finding treatments for diseases, it is imperative there be proper representation of everyone who would receive this treatment. Asthma, for example, is the most common childhood respiratory disease. It is most prevalent among Puerto Rican and Black children, with these children also having the highest mortality rates (1). White children only make up 9.5% of childhood asthma cases and are four times less likely to die from their illness. Yet, in a trial proving monoclonal antibody dupilumab to be a life-saving treatment for moderate-to-severe asthma, 90% of participants were of European origin. Because of this lack of diversity, there is no way to see the side effects and effectiveness of the drug on the same children who are most affected by asthma. This is just one example of the grave disservices done to non-white individuals seeking necessary treatment.

Many participants face barriers in getting involved in a clinical trial that they are unable to overcome without help. Issues like transportation, unclear informed consent clauses, distrust in the medical system, and extended time commitments can all deter needed prospective participants from signing up for clinical trials. These factors disproportionately impact those underrepresented in trials, hurting the quality of the data being produced.

Further information can be found in the recently released, congressionally mandated report from the National Academies of Sciences, Engineering and Medicine (2). I also penned a column recently on my personal experience with clinical trials (3).

In order to obtain the best information from clinical trials, it is imperative to have a truly representative pool of participants. By taking the small steps to tackle the hurdles between underrepresented groups and clinical trials, we gather better treatment and prevention of disease for everyone, avoiding unnecessary deaths and disabilities. With such a current focus on medicine, the time to repair clinical trials is now.

Thank you for your consideration,

David A. Crouse

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1. https://www.nejm.org/doi/full/10.1056/NEJMe2114944
2. https://tinyurl.com/3ekkf553
3. https://tinyurl.com/3ue5mhkb