

Utilizing a Lupus Clinical Trials Network to Advance Diversity and Representation in Clinical Trials: Perspectives, Preferences, and Unmet Needs of Patients, Providers, and Affected Communities

Investigators

- Saira Sheikh, MD - University of North Carolina at Chapel Hill
- Tessa Englund, PhD, MPH - University of North Carolina at Chapel Hill

Project Summary

There is an urgent need to improve the participation of racial and ethnic minority populations in lupus clinical trials to ensure that the products from clinical trials are safe and effective for all patients. Because of a high prevalence of systemic lupus erythematosus (hereafter, lupus) among racial and ethnic minority individuals, it is important to continuously increase diversity in clinical trials. It is necessary to explore and address multiple barriers and facilitators to improve diversity and representation in lupus clinical trials. This research employs a mixed-methods approach to collect, synthesize, and share insights to promote diversity in lupus clinical trials by engaging the Lupus Clinical Investigators Network (LuCIN) and affected communities. The findings will be used to develop an online toolkit for clinicians to increase diverse representation in lupus clinical trials and ultimately improve patient and public health outcomes.

Populations Served: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, White, and Hispanic or Latino

Goals/Aims:

- To leverage existing data to establish a multivariable dataset of participant- and site-level characteristics within the Lupus Clinical Investigators Network (LuCIN) network.
- To characterize the perspectives, preferences, and unmet needs of affected communities regarding strategies and solutions to improve recruitment of underrepresented populations in lupus clinical trials.
- To synthesize practical approaches and resources to improve diversity and representation in lupus clinical trials into a solutions-focused framework and inform the development of an online toolkit for clinicians to improve patient-centered clinical trials communication.

Publications/Abstracts/Posters, etc.

- [Barriers and Facilitators to Recruiting Underrepresented Participants for Clinical Trials: Insights from the Lupus Clinical Investigators Network \(LuCIN\) \[abstract\]](#). Arthritis Rheumatol. 2023; 75 (suppl 9).