Utilizing Patient-Centered Mobile Health Apps to Study Health-Related Quality of Life in Patients with Sarcoidosis and Other Rare Diseases
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Significance: The impact of sarcoidosis and other rare diseases on patient quality of life is poorly characterized and large-scale studies are lacking. It is difficult for these patients to find local resources and accurate disease information.

Innovation: Leveraging mobile technology to partner with patients with rare diseases will revolutionize the study of these diseases by capturing data on an unprecedented scale for a fraction of the cost of traditional studies.

Approach: We have successfully developed a mobile app for patients with sarcoidosis that we will use to conduct the largest study on sarcoidosis to date, determining the impact of the disease and its treatments on quality of life in an expansive range of patients. We will conduct a year-long prospective study using patient-reported outcomes to evaluate treatments, assess the impact of environmental and sociological factors on the disease, and elucidate potential etiologic triggers for the disease. The app also provides curated medical information to patients, including links to vetted informational and patient advocacy sites; an informational video; and interactive maps of local support groups and experts. In developing this mobile app and mobile device-based research project, we have ensured that the methods, partnerships, and protocols we developed are modular, widely applicable, and easily adaptable for similar projects so that other researchers at Penn can utilize this framework to study a wide variety of rare diseases.

Future Funding: This work will be a strong candidate for PCORI “Improving Methods for Conducting Patient-Centered Outcomes Research” and “Assessment of Prevention, Diagnosis, and Treatment Options” grants.