



## Using Research Techniques To Help Sickle Cell Patients

The National Institutes of Health — the Nation’s medical research agency — is committing substantial resources to increasing the scientific understanding of the needs of adults with sickle cell disease. AIR is part of that effort. Our scientists are developing a system to better understand the health-related quality-of-life issues facing patients with sickle cell disease.

AIR’s research draws upon patient reports to document and monitor the impact of the disease and its treatment on the daily lives of sufferers. The project director, Dr. San Keller, is a nationally recognized expert in the development of health-related quality-of-life measures and treatments for acute and chronic conditions. The project is funded by the National Heart, Lung, and Blood Institute.

Sickle cell disease is an inherited blood disorder that ultimately causes tissues to be deprived of appropriate blood flow. The immediate consequence is pain, potentially so severe that patients require hospitalization for weeks on end. Long-term consequences can include organ damage, joint necrosis, and death.

Until recently, this disease was a specialty of pediatric medicine because few sufferers lived to adulthood. Advances in treatment, however, now afford many with the disease to live into adulthood and even middle and old age. This has increased the demand for the care of adults with sickle cell disease, but medical practice patterns for adults with the disease are not well developed. Adults whose needs go unmet are at risk of dropping out of the medical system, risking rapidly deteriorating health.

The AIR project includes qualitative and quantitative research phases. The qualitative phase began with the use of the Critical Incident Technique that was invented



by John Flanagan, the founder of AIR. The technique involves an in-depth, one-on-one interviewing method that is especially useful in describing events that are poorly understood and understudied. Questions for the pilot study drew from the patient interviews. More than 500 adults from across the nation took part in the pilot test by completing a Web-enabled questionnaire in their doctor’s office. The questionnaire data were analyzed using advanced psychometric methods for which AIR is internationally known. The questions that provided the most precise and robust data were selected for inclusion in the patient-reported outcome (PRO) system. This system is a “smart” questionnaire that asks patients questions specifically tailored to them using item-response theory (IRT) and computer-adaptive testing (CAT) technologies.

The goal of the work is to improve the ability of medical providers to evaluate treatment options and enhance the quality of care being offered to patients. The fruits of this project should be better research methods to use not only for patients with sickle cell disease, but those who have other chronic conditions as well.

### About AIR

Established in 1946, with headquarters in Washington, D.C., the American Institutes for Research (AIR) is an independent, nonpartisan not-for-profit organization that conducts and applies behavioral and social science research to improve people’s lives and well-being, with a special emphasis on the disadvantaged.

The AIR Health Program offers a broad range of communication, research, creative, digital marketing, and management services.

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