What is the purpose of the study?
The purpose of this study is to better understand the ability of a questionnaire to collect information on gastrointestinal (GI) symptoms in patients diagnosed with cystic fibrosis. The questionnaire is intended to enable patients to privately report on their GI symptoms, eating challenges and enzyme adherence; and the effect that GI symptoms have on their quality of life. Use of this questionnaire will help to improve communication between patients and their healthcare providers with the goal of improving patient outcomes.

Who is eligible to participate in the study?
Patients with cystic fibrosis may be eligible to participate in this study.

What does the study involve?
Clinic staff will individually train patients on how to complete the electronic questionnaires using an iPad. At Visit 1, participants will also complete the Gastrointestinal Symptom Tracker (GI Symptom Tracker), Cystic Fibrosis Questionnaire–Revised (CFQ-R) and some additional questions regarding enzyme therapy that ask questions about the impact of cystic fibrosis and treatments on everyday life. Approximately half of the participants in this study will be selected to participate in a second clinic visit (10-21 days after the first visit). If selected, patients will complete the GI Symptom Tracker and enzyme replacement questions for a second time.

What are the benefits?
There are no direct benefits from taking part in this research. However, the medical information collected from patients participating in this study might be of possible future benefit to you and other patients diagnosed with cystic fibrosis.

What are the risks?
There are no additional health benefits or risks from participation.

Is there any compensation for participating?
An amount of $50.00 per visit will be provided to patients by the study site in order to compensate subjects for time spent completing study-related questionnaires. If subjects participate in both visits, a total of $100.00 can be received.

How will I get more information about the study?
If you are interested in learning more about this study, you can contact the principal investigator listed below.

Status: Recruiting
Site(s): Advocate Children’s Hospital, Oak Lawn and Park Ridge

Who should I contact for more information?
For Hope Children’s Hospital:
Javeed Akhter, MD
708-684-5810
Study coordinators: Bonnie Hughes, RN 708-684-3772 /Julie Connolly, RN, 708-684-3746
Email: bonnie.hughes@advocatehealth.com and Julie.connolly@advocatehealth.com

For Lutheran General Children’s Hospital:
Arvey Stone, MD
847-759-4770
Study coordinator: Suellen Moen, RN, 847-759-4770
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