

Research Findings for the Community

Title

Collecting patient preferences information across health systems: does it work with idiopathic pulmonary fibrosis?

What was the purpose of this research study?

It is important to understand patient preferences for treatments (e.g., what outcomes are important, which side effects are more or less tolerable, etc.) to understand the patient perspective. A challenge to conducting research about rare diseases like idiopathic pulmonary fibrosis (IPF) is that their small numbers make it hard to reach them. The goal of this research was to see if it is possible to survey patients about their preferences across a network of multiple health systems to increase the patient pool for the study. To test this, we asked patients about their preferences regarding benefits and side effects of two treatments for IPF. Dr. Ilene Hollin (at Johns Hopkins at the time of the study) led this research, working with the PaTH Network—a Clinical Data Research Network of six mid-Atlantic health system. Co-authors on the study included Anne EF Dimmock, John FP Bridges, Sonye K Danoff and Rebecca Bascom.

What questions were asked?

Is it feasible to collect patient preference data through a network of health systems?

What is the acceptability of side effects in IPF treatments?

What was the study design?

The study included adults with IPF, as determined by clinicians. Thirty-three patients participated. The majority of participants were over 65 years, married, and high school graduates. Fifty-four percent of participants were male and most had some form of health insurance. Participants completed surveys (either on paper or online). The survey presented patients with two hypothetical IPF treatments side-by-side. The two treatments differed in terms of their provided benefits and side effects, and the patient chose which treatment they preferred. They repeated this task 15 times with different hypothetical treatments.

What was discovered?

We were able to successfully survey patients about preferences across the network. Although we were able to quickly identify eligible patients, it was a challenge to get people interested in the survey. Despite the network, the sample size is still small. The treatment benefit most important to patients was the ability to slow the decline in lung function and the side effect patients most wanted to avoid was gastrointestinal problems.

What does this mean for my health?

When considering treatments for IPF, be sure to ask about side effects of medications and discuss what side effects are most tolerable to you. This may impact the choice of treatment.

Research article (literature citation)

Hollin IL, Dimmock AEF, Bridges JFP, Danoff SK, Bascom R. Collecting patient preferences information using a Clinical Data Research Network: demonstrating feasibility with idiopathic pulmonary fibrosis. *Patient Preference and Adherence*. 2019; 13:795-804.