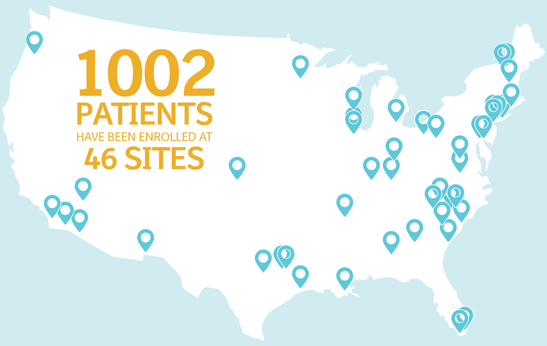
IPF-PRO™ ILD-PRO™

# Idiopathic Pulmonary Fibrosis Prospective Outcomes (IPF-PRO™) Registry

## Objectives

- The IPF-PRO Registry (NCT01915511) is a US registry of patients with IPF that was diagnosed or confirmed at the enrolling center in the past 6 months
- Data from the registry will improve understanding of the clinical course of IPF, its impact on patients, and practices in diagnosis and care[1]

## Sites and Patients




## Methodology

New or confirmed diagnosis of IPF

Retrospective data collection → Enrollment → Patients followed prospectively while receiving usual care

- Medical history
- Laboratory tests
- Diagnostic procedures
- Medications
- Comorbidities
- Patient-reported outcomes
- Pulmonary function tests
- Interactions with healthcare system

Follow-up visits approximately every 6 months

- Pulmonary function tests
- Interactions with healthcare system
- Listing for lung transplant
- Comorbidities
- Laboratory tests
- Medications
- Patient-reported outcomes
- Biological samples

Regular follow-up from a call center to confirm vital status and interactions with healthcare system and minimize missing data

## Characteristics of patients at enrollment

- Median age 70 years
- 75% male
- 67% current or former smokers
- Median FVC 70% predicted
- Median DLco 42% predicted
- 20% used oxygen at rest

Objective measures of disease severity such as lower FVC, lower DLco, and supplemental oxygen use were associated with worse scores on the St George's Respiratory Questionnaire (SGRQ)[2]

## Key findings to date

- Median time from symptom onset to diagnosis among patients who received a new diagnosis of IPF at the enrolling center was 13.6 months[3]
- Probability of hospitalization over 12 months' follow-up was ~ 30%[4]
- Probability of death or lung transplant over 30 months' follow-up was ~ 50%[5]
- Oxygen use at rest was the strongest predictor of death or lung transplant[5]
- Patient-reported outcomes assessing symptoms and physical activity provided prognostic information beyond clinical measures of disease severity[6]
- Mean annual cost per patient of inpatient hospital admissions was $14,000[4]


1. O'Brien EC, et al. BMJ Open Respir Res 2016;3:e000108.
2. O'Brien EC, et al. CHEST 2020;157:1188-98.
3. Snyder LD, et al. BMJ Open Respir Res; in press.
4. Fan Y, et al. CHEST 2020;157:1522-30.
5. Snyder L, et al. Respir Res 2019;20:105.
6. Case AH, et al. Ann Am Thorac Soc 2020;17:699-705.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