Discussion This methodological approach to item generation will enhance the content validity of the IPF-PROM instrument. Items generated to date will be modified further by 80 patients from 4 UK centres and 20 ILD physicians participating in 3 rounds of a Qualtrics Delphi survey. This study is ongoing.

M267 HEALTH STATUS AND QUALITY OF LIFE IN IDIOPATHIC PULMONARY FIBROSIS AND SARCOIDOSIS: EFFECT OF FATIGUE

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Introduction and Objective Sarcoïdosis and Idiopathic Pulmonary Fibrosis (IPF) are two common forms of interstitial lung disease. Sarcoïdosis frequently causes extra-pulmonary disease whereas IPF specifically affects the lungs. Fatigue is a common feature of sarcoïdosis, but an association between fatigue and IPF has not been investigated. We investigated the frequency and severity of fatigue in sarcoïdosis and IPF, how it correlates with disease activity, whereas it occurs as a sequelae of progressive disease severity.

Methods This was a cross-sectional questionnaire study of patients with sarcoïdosis and IPF. Questionnaire data was analysed to investigate health status, QOL, and symptom prevalence (fatigue, depression and sleepiness). Comparison of scores between groups, and an analysis of the effect of markers of disease severity (spirometry abnormality, immunosuppression use or extrapulmonary disease) were associated with fatigue scores. In IPF increasing dyspnoea scores were associated with increased fatigue scores (p < 0.001).

Conclusions Both sarcoïdosis and IPF patients suffer with high levels of fatigue, although the sarcoïdosis cohort showed a trend towards greater frequency of severe fatigue compared with IPF. In IPF patients increasing fatigue was associated with worsening dyspnoea, suggesting an association with disease progression, but no similar relationship was seen in sarcoïdosis. This suggests that fatigue in sarcoïdosis occurs independently of common markers of disease activity, whereas it occurs as a sequelae of progressive disease in IPF.
taking oxygen therapy. Patients may be left with feelings of anger at missed opportunities and concern for lost years of intervention and appropriate palliative care support.

**Conclusions** The diagnosis of IPF is a devastating one, which can be challenging to manage. Carers, patient groups and expert support at diagnosis were found to be invaluable to patients during this time.

**Results** The sample included 13 male and 3 female patients with IPF. Patients with lung function impairment of all severities were included, five patients were treated with oxygen therapy and another had received a lung transplant.

Many patients had a very active lifestyle before developing IPF, leading to a high degree of frustration with the limitations imposed on their physical ability. A protracted time to diagnosis of a rare lung disease while symptoms progressed often led to distrust with their primary healthcare physician. Lack of expert knowledge about the condition often resulted in variable handling of the situation, with patients often finding themselves in a type of “role-reversal” whereby they informed their primary healthcare physician about their own condition.

IPF specialists were perceived as their “guardian angels”. Despite being given a terminal diagnosis, patients felt reassured that they were receiving appropriate management for their condition. This stemmed from the perspective that specialists treating them had appropriate knowledge and a feeling they were supported by the specialist team.

**Conclusions** As with other rare diseases, patients appear to gain most reassurance from HCP’s with a clear understanding of their condition. This highlights the benefit of expert multidisciplinary teams for IPF.

**M269** THE EMOTIONAL TURMOIL OF IPF

**Background** Our aim was to understand the emotions patients experience in IPF, from initial symptoms to IPF specialist management.

**Methods** Market research was conducted with an independent agency. Patients with IPF were asked to record a personal account of their experience on a hand-held camera. Face to face interviews with patients were conducted in their home. Carers were also interviewed to add an alternative perspective.

**Results** The sample included 13 male and 3 female patients with IPF. Patients with lung function impairment of all severities were included, five patients were treated with oxygen therapy and another had received a lung transplant.

Many patients had a very active lifestyle before developing IPF, leading to a high degree of frustration with the limitations imposed on their physical ability. A protracted time to diagnosis of a rare lung disease while symptoms progressed often led to distrust with their primary healthcare physician. Lack of expert knowledge about the condition often resulted in variable handling of the situation, with patients often finding themselves involved in a type of “role-reversal” whereby they informed their primary healthcare physician about their own condition.

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**Conclusions** As with other rare diseases, patients appear to gain most reassurance from HCP’s with a clear understanding of their condition. This highlights the benefit of expert multidisciplinary teams for IPF.

**M270** OBTAINING INFORMATION WHEN YOU HAVE A RARE DISEASE – THE POTENTIAL FOR IPF SUPPORT GROUPS

**Background** The aim was to explore the ways in which patients with IPF obtain information about their condition.

**Methods** Market research was conducted with an independent agency. Patients with IPF were asked to record a personal account of their experience on a hand-held camera. Face to face interviews with patients were conducted in their home. Carers were also interviewed to add an alternative perspective.

**Results** The sample included 13 male and 3 female patients with IPF. Patients with lung function impairment of all severities were included, five patients were treated with oxygen therapy and another had received a lung transplant.

Patients reported finding information from a variety of sources, including primary healthcare professionals, patient information leaflets, the internet, district nurses and support groups. Most valued sources of information were IPF physicians, nurse specialists and patient support groups.

Gaps identified by patients were the need for high quality information including, 1) accurate and complete information about IPF, 2) clarity on the difficulty of predicting life expectancy, 3) how to access services and benefits, 4) how palliative care can help, 5) why support groups are beneficial, 6) how to modify lifestyle as capabilities change, 7) how to live and travel with oxygen and 8) how to explain oxygen to others.

**Conclusions** Support groups are under-developed, with great potential to help patients and their carers. Support groups are well placed to provide advice for everyday living that the healthcare community may be unable to offer. There is also a need to improve the standard of written information currently available for patients with IPF.

**M271** A SURVEY OF TRAINEE EXPERIENCES IN INTERSTITIAL LUNG DISEASE

**Background** The aim was to explore the ways in which patients with IPF obtain information about their condition.

**Methods** Market research was conducted with an independent agency. Patients with IPF were asked to record a personal account of their experience on a hand-held camera. Face to face interviews with patients were conducted in their home. Carers were also interviewed to add an alternative perspective.

**Results** The sample included 13 male and 3 female patients with IPF. Patients with lung function impairment of all severities were included, five patients were treated with oxygen therapy and another had received a lung transplant.

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