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

Results

- Sarcoioidosis cohort showed a trend towards greater frequency of severe fatigue compared with IPF.
- IPF patients increasing fatigue was associated with worsening dyspnoea, suggesting an association with disease progression, but no similar relationship was seen in sarcoioidosis. This suggests that fatigue in sarcoioidosis occurs independently of common markers of disease activity, whereas it occurs as a sequelae of progressive disease in IPF.

Conclusions: Both sarcoioidosis and IPF patients suffer with high levels of fatigue, although the sarcoioidosis 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 sarcoioidosis. This suggests that fatigue in sarcoioidosis occurs independently of common markers of disease activity, whereas it occurs as a sequelae of progressive disease in IPF.

**M268** THE IPF DIAGNOSIS – COMMUNICATING A LIFE SENTENCE

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Background The aim was to explore the patients’ emotional experience of receiving a diagnosis of IPF.

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. There was a national spread geographically throughout England.

There is a fine balance to providing information and patients can benefit from an individually tailored approach. Too much information at the start can be overwhelming. Too little information can leave the individual uncertain about how to deal with their future.

Gaps that were identified focused on the practicalities of living with IPF, including social care. There was a high expectation for their physician to explain the trigger for developing IPF. Patients felt a blame culture exists, whereby others felt that IPF is self-inflicted, like COPD, particularly when a patient was...
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.

**M269 THE EMOTIONAL TURMOIL OF IPF**

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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.

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 perception that specialists treating them had appropriate knowledge and a feeling they were receiving appropriate management for 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**

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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.