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.

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**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 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.

**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.
Abstract M271 Figure 1

M272 ESTIMATED COST AND PAYMENT BY RESULTS (PBR) TARIFF REIMBURSEMENT FOR IDIOPATHIC PULMONARY FIBROSIS SERVICES ACROSS 14 SPECIALIST PROVIDERS IN ENGLAND

Background Idiopathic Pulmonary Fibrosis (IPF) is an increasingly important respiratory illness in the UK. Rising prevalence of disease, emerging treatments, development of clinical guidelines for diagnosis and management and a NHS England service specification increase demands on healthcare providers who are required to enhance capacity or reconfigure services to manage patients.

Aims Estimate the patient care pathways across service providers in England compared with pathways recommended by NICE guidelines and the NHS England Service Specification; in terms of time and cost per patient by ‘diagnosis’, ‘management’ and ‘monitoring’, and then levels of reimbursement to providers for current levels of care and those recommended.

Methods Structured interviews with clinicians and coders ascertained current levels of service provision, excluding drug costs, by 14 NHS specialist ILD providers. Data were analysed utilising a bottom-up costing approach to estimate the total pathway costs. Comparison with services and costs as recommended by NICE guidelines and service specification allowed estimation of NHS providers’ profit or loss.

Results The estimated mean cost per patient for the first year of diagnosis, management and monitoring was £1,414, which is approximately £418 (42%) more than is reimbursed by the PBR tariff. By comparison, the equivalent cost of the NICE/service specification pathway is approximately £477 (41%) more than reimbursed by the tariff. In particular, it was noted that significant staff time is required for MDT discussion, but that this is not reimbursed.

Conclusions Results suggest that current NHS tariffs for ILD are insufficient to support current service provision. This is true for current levels of care as well as for the levels of care required...