

results were compared against one another using a paired t-test. Total of 46 sets of data collected.

Results Patients felt they were given more information about their diagnosis (mean 5.15 – >9.08, p value < 0.0001), prognosis (mean 4.76 – >9.04, p value < 0.0001) and treatment options (mean 4.63 – >9.28, p value < 0.0001). Patients felt they had more control over their disease (mean 3.67 – >6.66, p value < 0.001) and more confidence they were being managed correctly (mean 4.39 – >8.52, p value < 0.001). Patients felt more satisfied with their care after being seen at an ILD specialist clinic (mean 6.04 – >9.44, p value < 0.0001). More patients strongly agreed information given met their expectations (7/45 – >37/46) and was delivered in a way that was clear and easy to understand (11/45 – >36/45). 87% (40/46) of patients strongly agreed there is more benefit in being seen at a specialist centre.

Conclusion Evidence supports the utilisation of specialist centres to manage patients with ILD. Results show there is a significant improvement in patient understanding, experiences and satisfaction.

P276 DEVELOPMENT OF PATIENT REPORTED EXPERIENCE MEASURE (PREM) FOR IDIOPATHIC PULMONARY FIBROSIS (IPF)

¹AM Russell, ²S Sonecha, ³A Datta, ⁴R Hewitt, ²I Howell, ²A Elliott, ⁴M Wickremasinghe. ¹National Heart and Lung Institute, London, UK; ²Roche Products Limited, Welwyn Garden City, UK; ³Northwick Park Hospital, London, UK; ⁴Imperial College NHS Healthcare Trust, London, UK

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Background Research into patient experiences of living with IPF has increased. A key challenge is how to use this data intelligently to enable commissioners and providers to improve the quality of services delivered to this group of patients. This project aims to develop an IPF-PREM informed by patients’ perceptions of their healthcare experiences. The IPF-PREM is underpinned by the NHS Patient Experience Framework (NPEF);¹ National Institute for Health and Care Excellence (NICE) Quality Standards (QS15 and 79) and aligned to national initiatives integrating Patient Reported Outcome Measures (PROMs) and PREMs into NHS care.

Methods A scoping exercise was undertaken with patients diagnosed with IPF on their journey through the healthcare system covering eight areas corresponding to the NPEF.¹ Twenty patients representing all stages of the disease trajectory participated in one of three focus groups. Transcripts underwent content and thematic analysis. Patient preferences were also sought on questionnaire design.

Results A number of key themes emerged. See Table 1. Of particular importance were issues concerning access: to specialist centres, medication and primary care services; consistency of care to prevent confusion; coordination of care especially for patients with multi-morbidities and getting the right information at the right time in the right way. Information enabling practical self-management was highly valued. Overarching was the need for continuity of care close to home. Participants valued having a nurse to co-ordinate care and to talk to at *all* stages of the care pathway. The response categories patients were keen to avoid were visual images such as smiley faces.

Conclusions The IPF-PREM will provide a valuable quality indicator for IPF service delivery at all stages of the disease trajectory complementing IPF PROMs. Implementation of the PREM will enable commissioners and providers to improve the quality of the services and the patient experience of care delivered across the wider inter-disciplinary team.

REFERENCE

1 DH 2011 NHS Patient Experience Framework.

P277 MEASURING SEDENTARY BEHAVIOURS IN PATIENTS WITH IDIOPATHIC PULMONARY FIBROSIS USING WRIST-WORN ACCELEROMETERS

¹CP Atkins, ²M Baxter, ¹AP Jones, ¹AM Wilson. ¹Norwich Medical School, University of East Anglia, Norwich, UK; ²Norfolk and Norwich University Hospital, Norwich, UK

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Introduction Idiopathic pulmonary fibrosis (IPF) patients suffer increasing functional limitation as the disease progresses. Increasing sedentary behaviour (SB) time has been associated with poorer health-related quality of life. Determining thresholds for activity vigour in patients with respiratory disease is difficult due to variability in cardiorespiratory limitations between individuals.

Abstract P276 Table 1

NPEF domain	Focus group themes
Respect for patient-centred values	Recalibrating quality of life and wanting feedback on PROMs data; impact of breathlessness on independence; the need to talk and the need not to talk to be respected
Coordination and integration of care	Challenges of managing other health issues and lack of social/fiscal support – administrative processes often a barrier
Information, communication and education	The need to talk to others affected with IPF; more information at the beginning; to understand choices in healthcare; information customised to specific needs
Physical comfort	Impact on activities of daily life and how to physically manage these – support with transitions to oxygen therapy; need for effective symptom relief
Emotional support	Better access to psychological/counselling services for self and caregivers. Value having telephone support; healthcare professionals responding promptly to requests for advice. Wanting and not wanting to know prognosis
Involvement of family and friends	Family may have different information needs – respecting patient’s wishes – support for wives; husband’s; partners often lacking – guilt associated with burden of caring
Transition and continuity	Do not want to be abandoned at end of life – feel better supported by clinicians known at diagnosis. Value copies of correspondence. Value having a key contact – particularly specialist nurse
Access to care	Having a progressive condition makes waiting to be seen by a specialist centre or for transplant assessment stressful. Travel presents challenges: dichotomy of wanting care close to home but with specialist input; too many health care appointments