

## Developing a new pulmonary rehabilitation programme for interstitial lung disease

The Newcastle upon Tyne Hospitals NHS Foundation Trust provides a dedicated respiratory service for interstitial lung disease (ILD). Access to ILD-specific pulmonary rehabilitation (PR) is 1 of the 5 standards of care for people with ILD (NICE QS79). Our multidisciplinary team, in collaboration with Newcastle University and Marie Curie Hospice, designed a new service based on best practice, informed by NICE's guideline on idiopathic pulmonary fibrosis in adults: diagnosis and management (CG163).

*"This multidisciplinary approach to ILD rehabilitation has responded to patients needs and offers a unique and much valued service to patients and their carers."*

**Dr Ian Forrest**, Consultant Respiratory Physician and ILD Lead Clinician, Newcastle upon Tyne Hospitals NHS Foundation Trust.



### What we did and why

We were a regional centre for interstitial lung disease (ILD) but patients were attending pulmonary rehabilitation (PR) sessions for people with chronic obstructive pulmonary disease, so we did not meet the standard of care in terms of PR for this group.

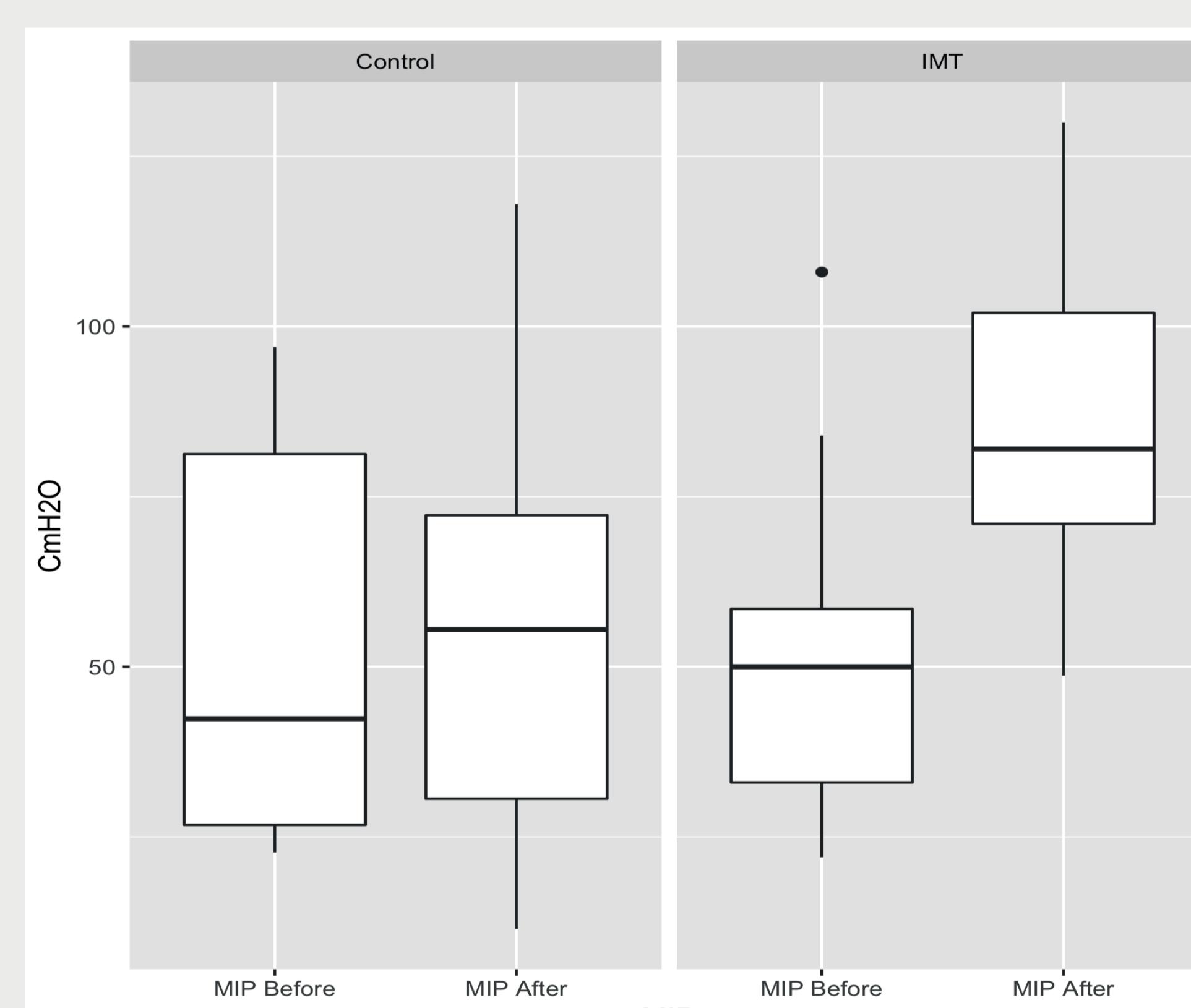
We set up an interest group that included patients with idiopathic pulmonary fibrosis to help develop a new day centre service. This was set up at Marie Curie Hospice in Newcastle upon Tyne. Patients attend once a week for 8 weeks to learn about their condition. Topics include:

- Pulmonary rehabilitation.
- Palliative care.
- Breathlessness management.
- Depression and anxiety management.
- Nutrition specific to ILD.
- Disease management.
- Maintenance exercise (including aerobics and strengthening work in the gym, plus a home exercise programme).
- Vaccination.

Health questionnaires are collected before and after the PR sessions. We also offer the PowerBreathe inspiratory muscle training device to some patients who are selected on a random basis.

### Outcomes and impact

28 people (25 men) with interstitial lung disease joined the programme. 24 of the group had idiopathic pulmonary fibrosis. More than 90% completed it (by attending the follow up session). More than 95% carried out all the exercises.



Among the PowerBreathe group, a 6-minute walk test showed that their maximum inspiratory pressure improved significantly. In addition, muscle strength and scores based on the King's brief interstitial lung disease questionnaire (K-BILD) and the fatigue severity scale (FSS) stabilised, despite lung function deterioration.

Based on this success and a growing patient list, the team decided to double the number of people accepted onto the programme.

### What we learnt

Previously patients attended pulmonary rehabilitation sessions twice a week. But people with interstitial lung disease (ILD) could attend once a week if they had a comprehensive home exercise regime.

This regime involves using therabands and pedals and increasing the repetitions and weights for each exercise each week.

The effect of the tailored exercises varies so it is essential to tailor them for each person. Patients were happy to use the Power-Breathe device and pedometers and they all completed their exercise diaries.

Because each session lasts 2 hours, carers, patients and the professional team have time to chat together. It also gives people time to ask questions during the education sessions.

The range of education sessions has been well received and overall feedback has been very positive. The service is now established and gaining a good referral rate. Completion rates are high.

The multidisciplinary nature of the team and their informal approach has helped both patients and carers gain a comprehensive understanding of ILD. It is viewed as a success by all concerned.