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Synopsis

Ambulatory Oxygen for Pulmonary Fibrosis (OxyPuF): a randomised controlled trial and acceptability study

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Plain language summary

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Idiopathic pulmonary fibrosis is responsible for as many as 1 in 100 deaths in the UK, killing 5300 people a year. Initially, sufferers notice shortness of breath and a persistent dry cough. As a result of breathlessness, patients reduce their physical activity; even basic tasks, such as washing, dressing and eating, can become difficult. Treatment may include exercise programmes (pulmonary rehabilitation), and tablets designed to reduce processes in the lung which lead to scarring (antifibrotics).

Increasing breathlessness can happen as a result of low oxygen levels, especially when trying to be active; it can even occur when oxygen levels are normal. There has been very little research into how to treat low oxygen levels for those with idiopathic pulmonary fibrosis; so far, there is no evidence as to whether using oxygen just for walking (ambulatory oxygen treatment) is helpful. This study planned to assess whether or not ambulatory oxygen therapy helped people with idiopathic pulmonary fibrosis. To test this, we designed a randomised controlled trial for 260 idiopathic pulmonary fibrosis patients who were breathless when walking.

We had difficulty finding centres and patients to participate; therefore, the trial stopped early, with only seven participants. These difficulties were affected by the impact of COVID-19 on conducting research across the country and unexpected financial issues relating to how treatment was delivered from different centres. However, interviews with people not participating in the study suggested the study would be unappealing to patients and healthcare professionals regardless of other factors. Analysis of data from 37 interviews (patients, clinicians and commissioners) concluded that ambulatory oxygen therapy was acceptable and widely (perhaps universally) available. Patients held strong views that it should be provided when required. We conclude that further trials of ambulatory oxygen therapy in idiopathic pulmonary fibrosis are not appropriate and that research in future should focus on improving support services and oxygen technologies.