



A lifetime of specialist care

PRESS RELEASE

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New study highlights lack of referrals for “life-changing” treatment

New research published today (11 August), led by respiratory teams at Royal Brompton Hospital, finds that patients feel they are having to “fight” to be referred for treatment procedures¹ that could have significant impacts on their length and quality of life.

The study, published in the *European Respiratory Journal Open Research*, collected the experiences of patients with emphysema who had a ‘lung volume reduction procedure’ at Royal Brompton Hospital in London or Glenfield Hospital in Leicester.

The procedures are suitable for some patients with chronic obstructive pulmonary disease (COPD), which damages parts of the lung, making it difficult to breathe. They work by removing damaged tissue, giving the healthy parts of the lungs more room to breathe. They sometimes involve an operation, but can also be done using a fibre-optic camera called a bronchoscope.

Despite lung volume reduction surgery being recommended by NICE as a treatment to be considered for patients with COPD, fewer than 100 patients undergo the procedure each year in the UK.

Dr Nicholas Hopkinson, honorary consultant physician at Royal Brompton Hospital said: “If you take a deep breath, so your lungs are nearly full, and then try to keep breathing in and out at that level you can experience what it’s

¹ “Patient experience of lung volume reduction procedures for emphysema – a qualitative service improvement project” (see Notes to Editors).

like to have COPD.

“These procedures can bring dramatic benefits to patients with COPD, so it’s a real concern that people who may benefit from them are not being considered to see if they might be suitable for treatment. There are over one million people with COPD in the UK and, while the procedures are only suitable for some patients, there are likely to be approaching 20,000 people who would benefit.

“If patients with COPD are on the right medical treatment, and have had exercise, education, and support – called ‘pulmonary rehabilitation’ – but are still breathless and have to stop even if they’re walking at their own pace, they might benefit from one of these treatments.”

Delays in diagnosis

One of the patients who took part in the study was Penny Rickman. Penny, 62, had been told since childhood that her shortness of breath was a result of asthma. It was only in 2002 – when Penny was 48 – that that she learned she had emphysema, a form of COPD which damages the air sacs (‘alveoli’) in the lungs.

Penny, who lives in Twickenham and is an account manager for design firm Alessi, said: “My symptoms would suddenly worsen and it felt like there was an elephant sitting on my chest. When it was particularly bad, it felt like the elephant was joined by a rhino, and then a hippo. I’d be really struggling to catch my breath at all. It was very frightening.”

Despite regular visits to her GP over the next nine years whenever her condition deteriorated, Penny wasn’t referred to a respiratory consultant for regular check-ups at her local hospital until 2011.

Penny’s lung condition deteriorated to the point where she was dependent on a portable oxygen concentrator. She remembers: “It was a real pain, dragging that with me absolutely everywhere – I couldn’t even Hoover or do the ironing

without it, let alone gardening or other hobbies. I couldn't walk anywhere without oxygen, not even to the bus stop, and I couldn't carry my shopping from my car to my house."

Penny was referred to Royal Brompton Hospital in 2014, where she was diagnosed with alpha 1 antitrypsin deficiency: a rare, inherited condition that can lead to people developing COPD early in life and may mean the disease progresses more quickly than usual.

New techniques

Doctors at Royal Brompton offered Penny the chance to take part in a clinical trial of a brand new technique for lung volume reduction: three special 'endo-bronchial' valves were implanted in her left lung, which allow air to leave damaged bronchi, but not to return. This reduced the amount of trapped air in the lungs and means Penny can breathe more easily.

Penny said: "It's completely changed my life. It feels like I can breathe again, and I can do things I love without using the oxygen at all. I can even go out with my friends without lugging it around with me now. The only times I need the oxygen now are when I go to the gym, to my pilates class or when I fly. The procedure has been absolutely life-changing for me."

Commenting on whether she should have been offered the procedure earlier, Penny says: "I didn't know it was available, I didn't know it was possible, I'd never heard of it. I just hope more people in my position ask their GP about whether they might be suitable, and I hope doctors realise what a difference it can make – I'm convinced it could benefit a lot more people."

Dr Hopkinson added: "We heard throughout this study that patients had to wait a long time before eventually being referred to a specialist. Health professionals may not know about recent advances in lung volume reduction treatments, they may not be sure how to refer or they may think that procedures are riskier than they really are."

“Sadly, patients described to us how they have to fight to be referred for these procedures, which could have a significant impact on their quality of life. It’s important that patients get the expert care they need at the right time and not when it is too late”

Dr Hopkinson is currently leading a clinical trial “the CELEB study” at Royal Brompton Hospital together with teams at Glenfield Hospital in Leicester and St Bartholomew’s Hospital in East London to compare the long term effectiveness of the two approaches for emphysema: valves and surgery.

Ends

Notes to editors

Research paper

The research paper entitled “Patient experience of lung volume reduction procedures for emphysema – a qualitative service improvement project” was published in August 2017 in the *European Respiratory Journal Open Research*. The lead author is Dr Nicholas Hopkinson of Royal Brompton & Harefield NHS Foundation Trust.

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Royal Brompton & Harefield NHS Foundation Trust is the UK’s largest specialist centre for the treatment of heart and lung disease. Working from two sites, Royal Brompton Hospital in Chelsea, West London, and Harefield Hospital, near Uxbridge, the Trust has an international reputation for the expertise of its staff, high standard of care and research success. Experts at the Trust help patients from all age groups who have heart and lung problems and provide some of the most complex surgery and sophisticated treatments available anywhere in the world.

The Trust is the UK’s largest centre for the treatment of adult congenital heart disease and is the country’s leading provider of specialist respiratory care. Over the years the Trust has been responsible for major medical breakthroughs, such as the UK’s first combined heart and lung transplant. It established the UK’s first adult service for cystic fibrosis, which is now one of Europe’s biggest treatment centres for the condition, and has pioneered the use of primary angioplasty for the treatment of heart attacks. Today the Heart Attack Centre at Harefield has one of the fastest arrival-to-treatment times in the UK, a crucial factor in patients’ survival.

As a member of the Academic Health Science Centre (AHSC), in collaboration with Imperial College London, Imperial College Healthcare Trust and The Royal Marsden NHS Foundation Trust, the Trust helps to drive innovation and improved care for over 1.1 million patients each year in North West London, by aligning the research, education and clinical services of the partner organisations. For more information, visit: www.rbht.nhs.uk/about/our-work/imperial-college-academic-health-science-centre-ahsc/

COPD

The Advanced COPD service at Royal Brompton Hospital includes a multidisciplinary team meeting at which patients with emphysema are discussed, involving thoracic surgery, respiratory physician and radiology, nursing and physiotherapy input. Conventional surgical procedures are considered, alongside more experimental interventions such as bronchoscopic valve placement.

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