

PETFIB Patient View Questionnaire

'PETFIB' is a trial to explore the potential of Cardio Pulmonary Exercise Testing as a biomarker in patients with a clinical diagnosis of FIBrosing lung disease. During the trial, we monitored how your lungs worked during a test on a stationary bike, and your health in general (weight, and blood tests) over several months

We are asking you these questions so we can understand your experience of participation in the PETFIB trial and to hear your views on the use of exercise testing to help with monitoring of patients with lung disease. Your answers will help us design future trials and inform how we assess the health of patients routinely.

The questionnaire is divided into two sections, one involving numerical scoring (some deliberately positive and some negative) and the other involving open questions.

Section 1

Please think back to when you took part in this trial and reflect on the following statements.

Please indicate how you feel about the following statements	Strongly Disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly Agree
	1	2	3	4	5	6	7
When I first heard about this trial I was keen to be involved							
My early understanding of what the trial would involve turned out to be unrealistic.							
The exercise test was too physically challenging for someone with my lung condition							
I was keen to complete the full trial despite medical and other challenges							
I have felt unsupported by the research team during my participation.							
Once I had given consent to be involved in the trial, I felt I could withdraw at any time							
Overall, involvement in the trial was a positive experience for me.							
Based on this experience, it is unlikely that I shall volunteer for future trials.							

Please indicate how you feel about the following statements	Strongly Disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly Agree
	1	2	3	4	5	6	7
I would advise other patients with similar conditions not to get involved in clinical trials like this.							
Based on my experience in this trial, I think cardiopulmonary exercise testing is feasible for lung disease patients.							
The idea of using exercise testing to develop individualised exercise programmes for patients does not appeal to me							

Section 2

Please reflect on the trial and answer the questions below.

1. What were your key reasons for getting involved in this trial?
2. Which aspects of the trial do you find most interesting and why?
3. How did you find the bike exercise tests and if you've done other exercise tests (like the shuttle walk test), which do you prefer and why?
4. What do you see as the benefits of having been involved?
5. What would you say have been the key challenges of being involved?
6. What do you think we should change to make it easier or better?
7. What else would you like to say or think is important?