



ARC East of England Treatment Preference Among People With Cystic Fibrosis

There is growing consensus that patient perspectives should be more emphasised when evaluating health and care interventions.

Cystic fibrosis patients are estimated to spend over 1.5 hours each day managing their condition, which has a substantial impact on their quality of life.

Surveys have identified simplification of this burden as a key priority. Understanding how patients perceive and prioritise potentially competing outcomes is increasingly important in the development and delivery of new CF interventions and

therapies. Despite a widening agreement that assessments of new interventions and therapies should include the patient perspective, there is no clear agreement on how this should be done.

What was the aim of the project?

To understand outcome preferences among people with CF and what 'trade-offs' between these they would be willing to make.

What did we do?

Almost 100 adults who attended a CF centre completed a survey in which they chose between potential CF management alternatives. Responses are used to understand how the differing outcomes of alternatives are valued.

How did we involve people?

People with CF were involved in all stages of the study, including developing the NIHR research proposal, designing the study, and understanding the results. The CF Trust kindly helped us identify volunteers to take part in focus groups that guided study development and a patient expert, Mark Rowley, who was part of the study team.

What is the impact so far?

Improving life expectancy was the most valued outcome; however, people with CF were prepared to accept substantial reductions in life expectancy and in lung function to reduce treatment burden.

Awareness of these outcome priorities will further inform decision making at both policy and clinic levels. They can also be used to inform the design of management

approaches. The findings from this study have been published in two papers, with a further two expected to follow this summer. This research has generated significant interest among the research community.

What next?

This study met its goals, but questions were raised about personal preferences affecting choices between outcomes and the impact of the UK's adoption of a new drug expected to have significant effects on CF. Therefore, we plan to refine the survey, collect additional information (addressing the questions above), and include more people with CF from across the UK. This new phase has received ethical approval.

For more information about this project

Scan the QR code or contact the Principal investigator, Dr Rory Cameron (rory.cameron@uea.ac.uk).



What is NIHR ARC East of England?

The National Institute for Health and Care Research Applied Research Collaboration East of England is one of the 15 NIHR ARCs. NIHR ARC East of England collaborates with Cambridgeshire and Peterborough NHS Foundation Trust, and the Universities of Cambridge, East Anglia, Hertfordshire and Essex along with other NHS Trusts, Local Authorities, Integrated Care Systems, patient-led organisations, charities, and industry partners.

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