

# Publications resulting from the James Lind Alliance (JLA) Priority Setting Partnership (PSP) in cystic fibrosis (CF) and James Lind CF2

## JLA PSP full papers

Rowbotham NJ, Smith SJ, Elliott ZC, et al. Adapting the James Lind Alliance priority setting process to better support patient participation: an example from cystic fibrosis. *Research Involvement and Engagement* 2019;5(1):24. doi: 10.1186/s40900-019-0159-x

Kalaitzis IS, Rowbotham NJ, Smith SJ, et al. Do current clinical trials in cystic fibrosis match the priorities of patients and clinicians? A systematic review. *Journal of Cystic Fibrosis* 2019;19(1):26-33. doi: <http://dx.doi.org/10.1016/j.jcf.2019.06.005>

Rowbotham NJ, Smith S, Leighton PA, et al. The top 10 research priorities in cystic fibrosis developed by a partnership between people with CF and healthcare providers. *Thorax* 2018;73(4):388-90. doi: <https://dx.doi.org/10.1136/thoraxjnl-2017-210473>

## Conference abstracts

Kalaitzis IS, Rowbotham NJ, Smith SJ, et al. How does the current clinical trials landscape reflect the James Lind Alliance top ten research priorities for CF? *Journal of Cystic Fibrosis* 2018;17 (Supplement 3):S130.

Rowbotham NJ, Smith S, Smyth AR. The top 10 research priorities for cystic fibrosis-whose priorities are they? *Pediatric Pulmonology* 2017;52 (Supplement 47):433. doi: <http://dx.doi.org/10.1002/ppul.23840>

Rowbotham NJ, Smith S, McPhee M, et al. Question CF: A James Lind Alliance Priority Setting Partnership in cystic fibrosis. *Journal of Cystic Fibrosis* 2017;16 (Supplement 1):S38.

Rowbotham NJ, Elliott ZC, Smyth AR. QuestionCF-the use of social media to engage the CF community in research. *J Cyst Fibros* 2017;16 (Supplement 1):S81-S82.

## James Lind CF2 full papers

Smith S, Rowbotham N, Davies G, et al. How can we relieve gastrointestinal symptoms in people with cystic fibrosis? An international qualitative survey. *BMJ Open Respiratory Research* 2020;7(1):e000614. doi: 10.1136/bmjresp-2020-000614

Calthorpe RJ, Smith SJ, Rowbotham NJ, et al. What effective ways of motivation, support and technologies help people with cystic fibrosis improve and sustain adherence to treatment? *BMJ Open Respiratory Research* 2020;7(1):e000601. doi: 10.1136/bmjresp-2020-000601

Rowbotham NJ, Smith SJ, Davies G, et al. Can exercise replace airway clearance techniques in cystic fibrosis? A survey of patients and healthcare professionals. *Journal of Cystic Fibrosis* 2019 doi: <https://doi.org/10.1016/j.jcf.2019.10.026>

Davies G, Rowbotham NJ, Smith S, et al. Characterising burden of treatment in cystic fibrosis to identify priority areas for clinical trials. *Journal of Cystic Fibrosis* 2019 doi: <https://doi.org/10.1016/j.jcf.2019.10.025>

### Conference abstracts

Smith S, Rowbotham NJ, Davies G, et al. Gastrointestinal symptoms in people with cystic fibrosis: a survey of lay and professional views. *Journal of Cystic Fibrosis* 2019;18 (Supplement 1):S137. doi: <http://dx.doi.org/10.1016/S1569-1993%2819%2930575-2>

Rowbotham NJ, Smith SJ, Davies G, et al. JLA CF2: Co-production of clinical trial outlines in partnership with the CF community. *Pediatric Pulmonology* 2019;54 (Supplement 2):464. doi: <http://dx.doi.org/10.1002/ppul.22495>

Rowbotham NJ, Smith SJ, Davies G, et al. Can exercise replace airway clearance? A survey of lay and professional views. *Journal of Cystic Fibrosis* 2019;18 (Supplement 1):S45. doi: <http://dx.doi.org/10.1016/S1569-1993%2819%2930262-0>

Herbert S, Rowbotham NJ, Smith SJ, et al. Relieving the burden of accessing medication: a quality improvement project. *Journal of Cystic Fibrosis* 2019;18 (Supplement 1):S179. doi: <http://dx.doi.org/10.1016/S1569-1993%2819%2930722-2>

Herbert S, Rowbotham NJ, Smith SJ, et al. Exploring the challenges of accessing medications for patients with cystic fibrosis. *Pediatric Pulmonology* 2019;54 (Supplement 2):379. doi: <http://dx.doi.org/10.1002/ppul.22495>

Davies G, Rowbotham NJ, Smith S, et al. Assessment of treatment burden and approaches to simplifying burden of treatment in cystic fibrosis: a mixed methods study. *Journal of Cystic Fibrosis* 2019;18 (Supplement 1):S187. doi: <http://dx.doi.org/10.1016/S1569-1993%2819%2930751-9>

Calthorpe RJ, Smith S, Rowbotham NJ, et al. What effective ways of motivation, support and technologies help people with CF improve and sustain adherence to treatment? A survey of lay and professional views. *Pediatric Pulmonology* 2019;54 (Supplement 2):415. doi: <http://dx.doi.org/10.1002/ppul.22495>

Rowbotham NJ, Smith SJ, Elliott ZC, et al. Understanding the treatment burden in cystic fibrosis: A step towards a trial of stopping treatment? *Pediatric Pulmonology* 2018;53 (Supplement 2):373. doi: <http://dx.doi.org/10.1002/ppul.24152>

### Related publications

Rowbotham Nicola J, Smith S, Prayle AP, et al. Gaps in the evidence for treatment decisions in cystic fibrosis: a systematic review. *Thorax* 2019;74:229-36. doi: [doi:10.1136/thoraxjnl-2017-210858](https://doi.org/10.1136/thoraxjnl-2017-210858) [published Online First: 9/10/2018]

Rowbotham NJ, Smyth AR. Patient engagement to prioritise CF research: Inclusive or selective?. *J Cyst Fibros*. 2019;18(3):307-308. doi:10.1016/j.jcf.2019.04.006

Rowbotham NJ, Smyth AR. The patient voice in research - Supporting actor or starring role?. *J Cyst Fibros*. 2017;16(3):313-314. doi:10.1016/j.jcf.2017.03.001