**Title:**

The changing face of cystic fibrosis research: challenges of multi-centre microbiology cohort studies

**Lay Title:**

The challenges of conducting large clinical studies in cystic fibrosis

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**What was your research question?**

We explored how the operation of large multi-centre clinical trials in cystic fibrosis changed over ten years between two major Australian studies that investigated microbiology in the lungs of people with cystic fibrosis. We asked: What has improved? What challenges remain? What obstacles might future CF cohort studies face?

**Why is this important?**

Cystic fibrosis care has changed significantly with CFTR modulator therapies that target the underlying cause of the disease. As patients experience fewer symptoms and infections, challenges have emerged in operating multi-centre studies that focus on biological and microbiological outcomes. Understanding past challenges can aid in the design of better studies for the future.

**What did you do?**

We compared two major studies to see how coordinating a multi-centre clinical study evolved over a decade. We examined the impact of CFTR modulator treatments on patient participation, sputum sample collection and detection of lung bacteria. We identified practical barriers such as securing funding and ethical approvals across multiple different hospitals.

**What did you find?**

Running large CF studies comes with both expected and unexpected challenges. As expected, changes in staff and limited funding made co-ordination across hospitals difficult. Unpredictable events such as the COVID-19 pandemic and the introduction of CFTR modulators had a major impact on study design and participation. Collecting sputum samples became harder as patients’ health improved and face-to-face clinic visits became less frequent. Future research must be flexible and well-supported (finances and staffing) to adapt to changing conditions and continue delivering meaningful results for people with cystic fibrosis.

**What does this mean and reasons for caution?**

Despite the challenges, multi-centre cohort studies remain vital for understanding the changing landscape facing cystic fibrosis. Researchers need to plan carefully and be flexible to adapt to evolving challenges.Improved health outcomes may reduce patients’ willingness to take part, limited access to research funding and delays in ethical approval make research harder to commence and sustain. Addressing these barriers is key to continuing meaningful research and improving care.

**What’s next?**

Future studies must adapt to improved patient health, reduced sample availability, and evolving health care facing research environments. Building strong collaborations, securing funding early, and streamlining approvals will be key to successfully conducting meaningful cystic fibrosis research.

**Original manuscript citation in PubMed**

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