Cystic Fibrosis Trust

Understanding lived experience of people who face structural barriers to living well with CF

(focusing on people affected by CF who are neurodivergent, or who are from UK Minority Ethnic Groups)

Invitation to Tender

Uniting for a life unlimited

1. Introduction

Cystic Fibrosis Trust is inviting tenders from suitably qualified individuals or organisations to undertake a qualitative research project exploring the lived experience of people with cystic fibrosis (CF), with a particular focus on how neurodiversity or ethnicity can impact on the care, treatment and management of the condition and may act as barriers to accessing support, information and services.

The maximum value of this contract is £20,000 (inclusive of VAT and all associated costs).

This project has been funded by Vertex Pharmaceuticals.

2. Background and context

Cystic fibrosis is a complex, lifelong condition requiring extensive care, treatment and support. There is growing recognition that people with CF who are neurodivergent or from UK ethnic minority backgrounds may experience barriers that can negatively impact their experiences of CF, the care and treatment they receive, and their physical and mental health and wellbeing. These can include communication challenges, cultural factors, lack of access to effective treatments, lack of tailored information, and difficulties accessing appropriate support. People from non-white backgrounds are less likely to be able to access new treatments (CFTR modulators) that have changed the health outlook for many with CF.

Everyone affected by CF deserves to live a life unlimited. To make that a reality, we must first understand and address persistent inequalities that leave some people within the CF community isolated, unsupported and unable to access the care they need.

At present, there is limited research that captures the lived experience of people affected by CF from these groups. This project aims to address this gap and provide evidence to inform more inclusive and equitable services and support.

Findings will support our internal inclusivity strategies and will be shared with CF centres, NHS professionals, and international colleagues to promote equity in CF care and support.

3. Aims and objectives

The overall aim of this research is to generate robust, lived-experience-led insight that can inform policy, service design, information production and accessibility.

- Explore the lived experiences of people with CF who are neurodivergent or from UK ethnic minority backgrounds.
- Identify barriers to living well with cystic fibrosis, particularly barriers to accessing support.

- Understand how neurodiversity and ethnicity intersect with CF to shape experiences of life with the condition.
- Identify examples of good practice in the provision of support
- Highlight unmet support needs.
- Produce clear, practical recommendations to improve access to and experience of support.

4. Scope of work

To design and deliver an inclusive and accessible research project, using mixed methods, which meets the project brief and requirements, including:

- working with a project steering group of people affected by CF who are neurodivergent and/or from an ethnic minority background to shape the research (at least two people representing each group)
- advising on appropriate level of ethics approval and ensure any required approval is in place
- engaging meaningfully with people with lived experience of CF, including people with CF and those who care for them (project aim = 20 participants)
- ensuring accessibility in recruitment, communication methods and participation
- taking account of systemic, cultural and structural factors affecting access to support.

Research methods may include interviews, online focus groups, surveys, and participatory or co-production approaches, and should be planned with the specific needs and accessibility requirements of people affected by CF in mind. Innovative approaches that centre lived experience are strongly encouraged. Research with participants can be conducted remotely but must consider potential barriers relating to digital exclusion.

Steering group and project participants will be adults (aged 18+), and will include 50% representation from parents/carers of children with CF.

5. Outputs and deliverables

- A final written research report setting out findings, analysis and conclusions.
- A clear set of evidence-based, practical recommendations.
- An executive summary suitable for a non-specialist audience.
- A suitable abstract/poster format for submission to conferences.
- Accessible or alternative formats such as easy-read summaries or visual outputs (subject to budget).
- Presentation of findings at relevant internal and external events/conferences.

6. Timescales

The anticipated duration of the project is approximately 7 months with an expected start date around mid-October 2026. Bidders should include a detailed project plan with milestones.

7. Budget

The maximum available budget for this project is £20,000 inclusive of VAT and expenses. Tenders must include a transparent and detailed budget breakdown. Value for money will be a key assessment criterion.

8. Ethical, equality and safeguarding considerations

Bidders must demonstrate a robust ethical approach, a commitment to equality, diversity and inclusion, and appropriate safeguarding arrangements, particularly where children or vulnerable adults are involved.

9. Tender submission requirements

1. Proposed methodology and approach
2. Evidence of relevant experience and expertise
3. Project plan and timeline
4. Detailed budget
5. Equality, diversity and inclusion considerations
6. Ethical and safeguarding approach
7. Confirmation of ability to work as an independent freelancer (e.g. Have your own office/IT equipment and the correct tax and NI status to work as a freelancer), and own software/equipment required for the project.
8. Evidence of any professional indemnity insurance/public liability insurance you have in place.

10. Evaluation criteria

- Quality and suitability of approach
- Understanding of lived experience: while lived experience of cystic fibrosis (or disability/long term health conditions) is not an essential criterion, given the additional relevant knowledge and understanding it would bring to this project, it will be viewed as a distinct advantage when tenders are evaluated.
- Relevant expertise
- Equality and accessibility
- Value for money
- Ability to meet timescales

11. Submission details

Deadline: midnight 18 September 2026
We may carry out interviews with shortlisted bidders in late September 2026.

Submission method: Please submit by email to
becky.kilgariff@cysticfibrosis.org.uk

Contact for queries: **becky.kilgariff@cysticfibrosis.org.uk**