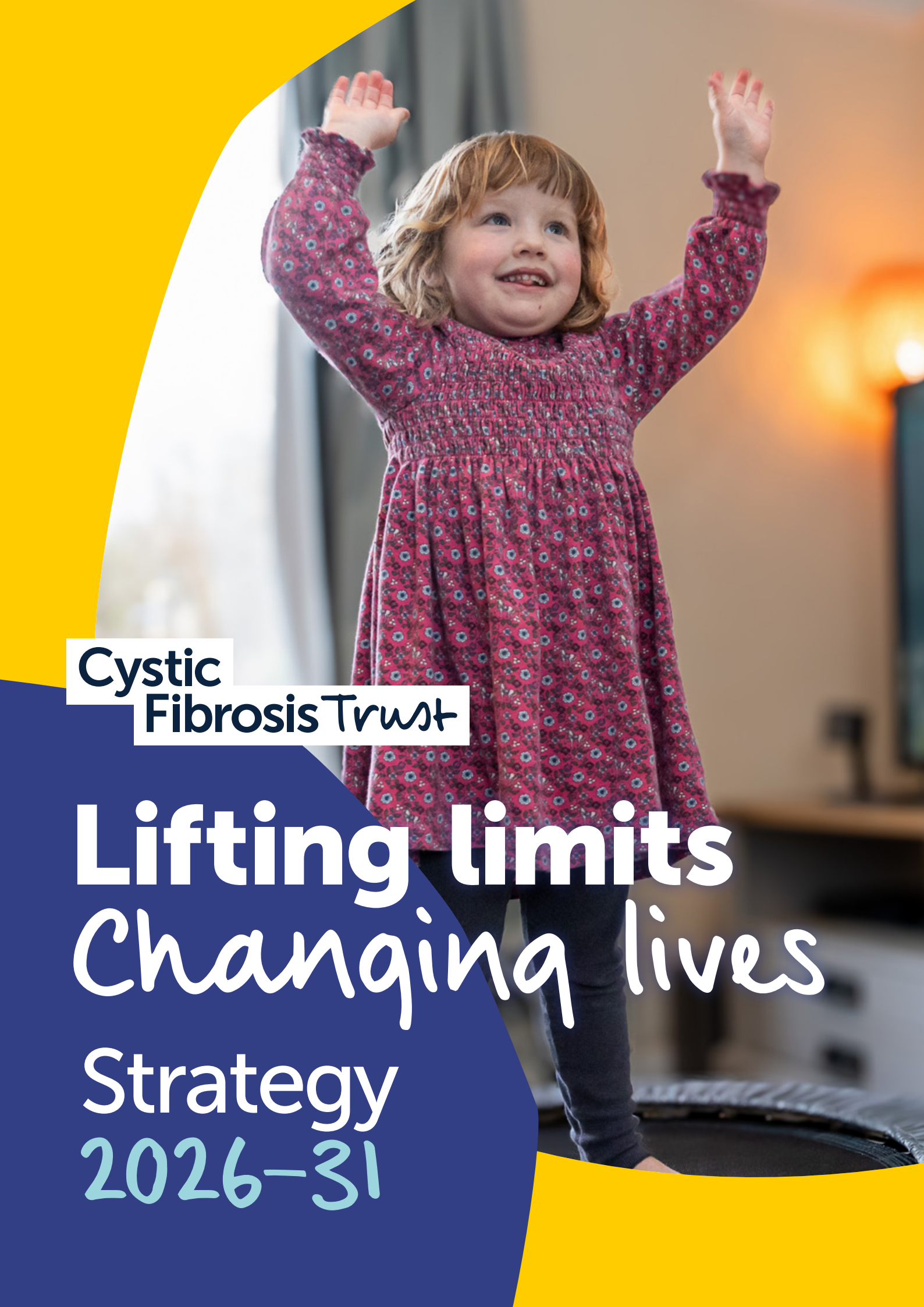




**Cystic
Fibrosis Trust**

Lifting limits *Changing lives* **Strategy** **2026-31**





Lifting limits Changing lives

Strategy 2026–31

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Thank you

This strategy reflects the views and experiences of thousands of people affected by CF and the wider CF community. Our understanding and priorities have been shaped by insights from UK CF Registry data, our Community Involvement Group, the research priority setting process we carried out with the James Lind Alliance, surveys, focus groups, discussions at our clinical and research conferences and events, and many other inputs.

Thank you to everyone who has shared their hopes and ambitions with us.



Our vision and goals

Cystic fibrosis limits lives. We're here to change that. We fund vital research, improve care, speak out, and race towards effective treatments for all. Our vision is a life without limits so that everyone with CF can live a long and full life.

Our context

Cystic fibrosis (CF) is a lifelong, life-limiting condition with no cure. The condition has a significant impact on health, daily life, and life expectancy. Based on the latest median predicted survival data, half of people with CF are expected to live to at least 70, but half are expected to die before that point. The median age at death for someone with CF is just 36.

CF makes life too hard and too short for too many.

For much of the last decade, we have campaigned for the widest possible access to CFTR modulators. This has delivered significant progress, with people in the UK now having global-leading access to the best available treatments.

But CFTR modulators are not a cure, and they don't work for everyone. People from ethnic minority backgrounds are disproportionately affected as they are more likely to have rarer CF genotypes that mean they cannot benefit from these treatments. We also don't yet know the long-term impact of modulators.

Importantly, everyone with the condition continues to need specialist care, information, and support.

The reality of CF today

CF affects the whole body. As well as problems with lung health, many people experience gut and liver difficulties, CF diabetes, infertility, increased risk of other conditions, including some cancers, and mental health challenges. Intense treatment and care place a very high burden on people with CF and their families.

- Around 1 in 5 people with CF still regularly need intravenous antibiotic treatments.
- On average, people with CF take 34 tablets a day, with some taking over 100.
- 28% of over 10-year-olds have treatment for CF diabetes and 23% of those over 16 with CF have liver disease.
- Around 80% take pancreatic enzyme supplements.

Advances in treatment and care mean the UK CF population is growing and changing. More than 11,600 people with CF now live in the UK, and around 65% of people on the UK CF Registry are aged 16 or over, including more than 300 people aged 60 or over.

The economic, social, and care needs of people affected by CF in the UK are also becoming increasingly diverse and complex. Additionally, some people face barriers like insecure housing, poverty, neurodiversity, or low literacy.

Living longer with CF in a changing world

This is a time of progress and uncertainty.

The widespread availability of modulators has transformed many lives but has also affected the research landscape in CF and reduced the number of people available for some clinical trials. With urgent new research questions to answer as people live longer, investment is critical to protect and build on the achievements we've seen.

At a time when the care needs of people with CF are changing at pace, the traditional NHS model of multidisciplinary CF care is under pressure from workforce challenges, resource constraints, and changes to how care is commissioned and delivered.

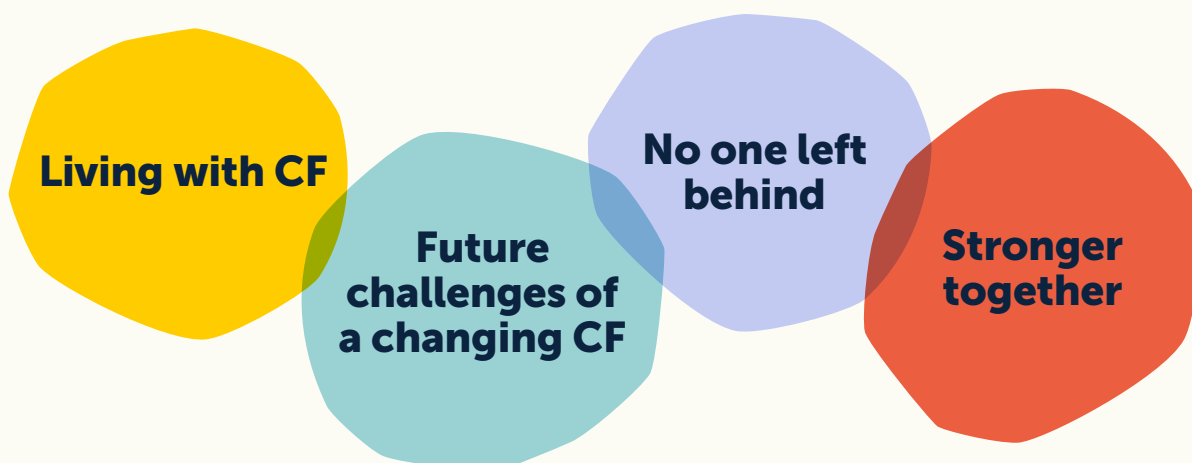
We also know that the need for specialist psychological and social work support is increasing, while staffing and resources remain limited. Ensuring that everyone with CF can access the specialist, multidisciplinary care they need is vital.

As people are planning for futures and life stages they may never have expected, they have new information and support needs, from family planning to pensions. They are also impacted by external forces from extreme weather events and global medicine supply chain disruptions to cost of living pressures.

CF limits lives. We're here to change that.

Our impact goals

Led by the insights of the CF community, we have identified four strategic impact goals that will drive our activity over the next five years.



Tackling the daily challenges

CF affects your physical health, mental health, and many other aspects of daily life, from education and work to relationships and travel.

As the only UK-wide CF charity, we need to make sure that everyone gets the care, information, treatments, and support they need today to manage their CF and live a long and full life.

We want a future where:

- CF care is holistic, high quality, fit for the future, data driven, and informed by the needs and priorities of people with CF.
- the diagnosis and treatment of complications and symptoms of CF, such as lung infections, is improved and translated into clinical practice.
- everyone can access timely, high-quality, accessible information on topics that matter to them about living with CF.
- everyone can access our support, advice, and signposting when they need us.
- there is strong awareness, understanding, and action on the issues affecting the health and wellbeing of people with CF.

We will:

- develop and deliver timely, accessible, high-quality, and trusted information content that responds to a changing digital landscape.
- ensure that everyone affected by CF can access support, advice, and signposting when they need it.
- work with people with CF and the UK CF clinical community to set and promote high standards of care, ensuring the diverse needs of the CF population are understood and represented.
- advocate with and for everyone with CF to have access to high-quality specialist care, support, and treatments, wherever they live.
- campaign and provide support to tackle the costs of CF and promote more flexible and supportive approaches to education and employment.
- campaign for improvements to air quality, housing conditions, and other factors that affect health and wellbeing.
- create opportunities for healthcare professionals and people affected by CF to share learning, innovation, and experiences as CF care continues to evolve.

Responding to new challenges in CF

As more people with CF live longer, new challenges and uncertainties are emerging.

People with CF may face a wider range of health issues and co-morbidities as they age, including increased risk of some cancers. They may also need support with other challenges like balancing education, work, or having a family with the tough reality of living with CF.

Future challenges of a changing CF

We want a future where:

- research enables people with CF to live longer, healthier lives.
- treatments are developed and available for all aspects and symptoms of CF.
- we have a more complete picture of healthcare for people with CF by combining Registry data, linked health data, and lived experience.
- people with CF are empowered, through access to information and their health data, to understand and better manage their CF and complications.
- the long-term treatment, care, and information and support needs of an ageing UK CF population are understood and addressed, including through access to the right screenings, treatments, and technology.
- the UK CF Registry continues to evolve to meet the changing needs of an ageing and increasingly complex CF population while remaining a world-leading resource for research and care.

We will:

- accelerate research into new and better treatments for all aspects of CF.
- anticipate and respond to the health and other needs that come with living longer with CF, including supporting people with CF to understand and manage their CF as they encounter new complications or comorbidities.
- use community feedback alongside UK CF Registry, Patient Reported Experience Measures surveys (PREMs), and quality improvement (QI) data to address inequities, support changing care needs, and make the case for sustained investment in CF specialist care.
- continue to develop the UK CF Registry so it keeps pace with a changing CF population and remains a trusted, world-leading resource.



Our research goals

Our research goals are based on what people affected by CF told us matters most through the James Lind Alliance Priority Setting Partnership. They are:



Developing effective treatments for all

We are committed to ensuring everyone with CF can benefit from transformative treatments. Around 5% of people with CF cannot currently benefit from modulators. They must remain a priority in the research we fund and support.



Improving the diagnosis and treatment of CF lung infections and maintaining lung health

We will support research to improve lung infection diagnosis, reduce the negative effects of antibiotics, including antimicrobial resistance, and advance understanding of how to protect lung health throughout life.



Treating all of the symptoms of CF throughout the body

We will support research into CF-related complications, including CF diabetes, gastrointestinal symptoms, bone disease, liver disease, and sinus complications, while improving understanding of how CFTR modulators affect symptoms throughout the body beyond the lungs.



Enabling people with CF to live longer lives

We will support research into the physical and mental health challenges of ageing with CF, including age-related health complications, long-term effects of modulators, reducing treatment burden, and menopause, fertility, and pregnancy.

Addressing health inequalities

Some people with CF face different and extra barriers to staying well and living a full life.

Modulator therapies don't work for everyone. Some types of CF are unresponsive, while some people cannot tolerate them.

People who are from ethnic minority backgrounds or face other barriers that can impact their health, like poverty, neurodiversity, or low literacy, may need additional support.

No one left behind

We want a future where:

- everyone gets the treatment, care, and support they need.
- effective treatments are developed and accessible for all, including those who cannot benefit from current treatments.
- the needs of people who face additional barriers that affect their CF health are recognised and addressed.

We will:

- raise awareness and address the specific challenges of those facing additional barriers that impact their health, starting with people who:
 - cannot benefit from modulators
 - have had a lung transplant
 - are from ethnic minority backgrounds
 - live in poverty.
- prioritise research that addresses the needs of people who cannot benefit from current treatments or face additional barriers to good health.



Creating opportunities for connection and support

Stronger together

CF is a rare condition, which can be very isolating for people affected by it.

Cross-infection guidance means people with CF are advised not to meet in person, making it harder for people to support each other. Low awareness and understanding of CF can mean people must repeatedly explain the condition and advocate for themselves. Through shared experiences, peer support, fundraising, and campaigning, people affected by CF can build connections and drive powerful positive change.

We want a future where:

- people affected by CF feel less isolated, through greater connections and mutual support.
- the diverse voices and priorities of people with CF inform our work and shape everything we do.
- people with CF can safely participate in a diverse range of fundraising and other activities to have impact and influence the future.

We will:

- ensure all our work is informed and shaped by the lived experiences and insights of people affected by CF.
- create opportunities for people with CF, their support circles, and families who have lost loved ones to connect, share their stories and experiences and support each other.
- fundraise in new and innovative ways that enable as many people living with CF as possible to take part.



A man with curly hair and glasses is shown in profile, using a nebulizer. He is holding a smartphone in his left hand and the nebulizer in his right hand. The nebulizer is a white device with a blue mouthpiece and a blue tube. The background is a dark blue wall with vertical lines. The text 'Our capabilities' is overlaid on the image in a large, white, sans-serif font.

Our capabilities

To maximise our impact and income and achieve our goals, we need to continue to build and strengthen our internal capabilities. This means

Supporting research infrastructure, including clinical trials and the UK CF Registry

Research is essential to developing new treatments, improving care, and ensuring everyone with CF can benefit from advances in understanding and treatment.

Our research goals are supported by research infrastructure, which brings together expertise, data, community insight, and partnerships. This includes the UK CF Registry, which collects longitudinal data from more than 98% of people with CF across all 61 UK centres, and our patient and public involvement and engagement (PPIE) expertise, which ensures the lived experiences and priorities of people with CF inform research. We also lead and support research networks and clinical trial delivery. This is underpinned by our data analysis expertise and partnerships with academic institutions, NHS centres, and industry collaborators.

We will:

- continue to adapt how we deliver our research goals while remaining guided by the needs of people affected by CF.
- continue to develop the UK Clinical Trials Accelerator Platform (CTAP), our national network of CF trial centres, ensuring people with CF across the UK can access clinical trials regardless of where they live, and attracting investment into CF research.
- invest in the future development and sustainability of the UK CF Registry, modernising its systems and strengthening how its data is shared securely to meet the changing needs of the NHS and drive improvements in care and treatment as the health data landscape evolves.

Centring the lived experience of people with CF

Our patient and public involvement and engagement (PPIE) work ensures that the knowledge and experience of people living with CF, and those who support them, informs all our work. This is underpinned by our Community Involvement Group, a network of over 350 people affected by CF who take part in focus groups, advisory panels, document reviews, and other activities. Insights are captured and shared through our CF Insights Library. We also work closely with industry partners to embed PPIE in commercially funded research, ensuring insights from people affected by CF shapes clinical trials from the earliest stages of design.

We will:

- continue to grow and diversify our Community Involvement Group so that it reflects the full breadth of the people affected by CF in the UK.
- ensure the voice of people with CF shapes decisions across the Trust.
- work with industry to embed the voice of people affected by CF in commercially funded research so that clinical trials are well-designed and focused on what matters most to people living with CF.
- build on our reputation as a sector leader in involvement practice, sharing what we learn with the wider CF community nationally and internationally.

Attracting and retaining talented, diverse, and committed people

Our staff are at the heart of everything we achieve. To deliver meaningful impact for everyone affected by CF, we need to attract, develop, and retain exceptional people. To achieve that, we need everyone to feel welcome, heard, and supported from their very first interaction with the Trust.

We will:

- continue to strengthen our workplace and culture, ensuring everyone feels welcome and respected, and is able to thrive.
- actively monitor whether we have the skills, capabilities, and culture we need to deliver our strategic goals, taking action when needed.
- listen to staff to understand what they need to do their best work.
- enable high performance by providing clarity on responsibilities, expectations, and how each role supports our strategy, and by continuing to strengthen our commitment to learning, development, and innovation.
- continue to bring our values to life through our work:
 - Together : reflecting the diverse experiences of everyone affected by CF and making sure that the Trust is a truly inclusive workplace
 - Trusted : ensuring that our work is informed by evidence and can be trusted by everyone affected by CF.
 - Unstoppable : taking considered risks and innovating to push for changes that will improve lives.

Ensuring that we have great data, systems, and technology

Beyond the role of the UK CF Registry, data drives our fundraising, enables us to learn, and powers our networks and day-to-day operations. Optimising this data, and the systems and technologies that enable us to collect, check, store, report and learn from it, is crucial to our ability to deliver our goals.

We will:

- actively monitor emerging technologies, including AI, to consider how new tools can be used appropriately to enable the Trust to deliver more for our community and become more effective as an organisation.
- deliver a modern, flexible Customer Relationship Management (CRM) platform which will enable us to work in new ways and deepen our relationships with supporters.
- continue to ensure that our data is held in a compliant, secure way.
- develop the tools and skills we need to understand, learn from, and use our data.

Sustainable fundraising and commercial income

We only exist because of the generous support of individuals, funders, trusts, corporate partners, and people who leave gifts in their Wills. We are incredibly grateful to everyone who supports us. We know that times are tough, with world events impacting the cost of living in the UK. This has made it more important than ever to find sustainable funding, with ongoing or multi-year commitments wherever possible, which enable us to protect the future of our services.

We will:

- innovate to grow a dynamic portfolio of fundraising products and grow our supporter base, making the most of digital advances to attract and retain supporters.
- create more opportunities for people with CF to get involved and mobilise their networks.
- seek out and support more strategic partnerships with funding organisations and continue to build and scale our commercial offering.

Working in partnerships and collaboration

One way to amplify our impact is by working with others. We already co-fund major research programmes, work alongside the life sciences industry to accelerate the development and testing of new treatments, and partner with other charities to deliver support and campaign for change.

We are always looking for partners who share our goals and values and want to work together to make a difference for people living with CF. These partnerships could be on the basis of funding, skill-sharing, adding voices to campaigns, or building projects or programmes jointly.

We will:

- Continue to build joint programmes with partners such as LifeArc, Medicines Discovery Catapult, the Cystic Fibrosis Foundation, the European Cystic Fibrosis Society, CF Europe, and other CF patient organisations to extend the reach and impact of what we can achieve alone.
- Work closely with people affected by CF, partners and decision-makers to build understanding and awareness of the condition and drive meaningful change.
- Reach beyond the CF field to build relationships with organisations working on other conditions where priorities and unmet need overlap, bringing additional expertise and capabilities into CF research, care, and support.





As the UK's only national CF charity,
we fund research, improve care,
provide practical support, and
campaign on the issues that matter
most for everyone affected by CF.

**We're here to lift the limits CF brings.
Together we'll help everyone with CF
to live a long and full life.**

cysticfibrosis.org.uk

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