Cystic Fibrosis Trust

CF workforce survey insights 2025

"The workload has just changed, not gone away."

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Uniting for a life unlimited

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We are also very grateful to our Clinical Advisory Group, Quality Improvement working group and several volunteers from CF professional groups who fed into development and testing of the survey. Finally, we would like to thank all CF professionals who took the time to respond to the survey and so generously shared their views and ideas.

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Cystic Fibrosis Trust

CF workforce survey insights 2025

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Summary

Participation and feedback

The CF workforce survey collected data between mid-March and mid-April 2025. Overall, 152 responses were received from health professionals working in CF centres and clinics across the UK.

Key insights

CF professionals report significant changes in population needs and CF care, mainly driven by modulator therapies, but wide-ranging in their impact:

- Care delivery is shifting away from acute and inpatient care to more outpatient, remote, and preventative models, with an emphasis on long-term management and quality of life.
- Population needs are diversifying. Some patients still require mainly respiratory and acute care, while many others now present with a wider range of issues, including gastrointestinal (GI) symptoms, CF diabetes, mental health problems, and neurodiversity.
- Complexity is increasing, with new demands arising particularly in adult care around fertility, pregnancy, menopause, and conditions of ageing.

Overall workload for many CF professionals is evolving, rather than reducing:

- 70% of respondents reported working more than their contracted hours on clinical CF work, rising to 74% for non-clinical work.
- 13% of our respondents gave a low rating for the match between day-to-day work and their original role description, suggesting that, for some professionals in CF, day-to-day activities delivered are diverging significantly from original role descriptions.

Professionals working in CF face a number of challenges:

- Staffing and resourcing issues, which also affect the wider NHS, are impacting CF teams in terms of capacity, recruitment and succession planning, as well as funding and time for training and development.
- Changes in models of care, funding arrangements, and technologies require CF professionals to develop new skills, and to rapidly adapt behaviours and practice.
- Care delivery was impacted by medicine supply shortages, limitations on physical spaces available to CF teams, as well as new and increasing demands on CF professionals.

Over 80% of our respondents remained optimistic about the future of CF care and their teams' ability to adapt, though they were less optimistic about future funding.

CF professionals' top priorities for improving CF care focused on:

- Equitable access to treatment and support, while reducing the overall burden of care for all people living with CF.
- Delivery of holistic, person-centred care that adapts around patient needs and empowers people with CF and their families.
- Continued education and development, as well as enhanced collaboration within and beyond CF teams, to ensure care can meet the changing and diversifying needs of the CF population.

Recommendations

For care delivery

- Ensure there is equitable access to care and treatments for all people with CF and address medication supply issues.
- Where appropriate, shift the focus of care to more holistic, preventative approaches to enable people with CF to live a fulfilled life, but retain capacity to deliver high-quality acute care for those who still need it.
- Empower patients:
  - Provide the support and resources needed to self-manage where feasible.
  - Try to accommodate preferences, e.g. for appointment format and frequency.
  - Involve service users in designing new models of care and services for CF.
- Reduce burden of care by leveraging technology and implementing more flexible, person-centred approaches to care.

For team development and ways of working

- Support CF professionals to maintain skills, and junior staff to develop skills, to care for all people with CF, including those requiring more traditional CF care.
- Support CF professionals to access training and resources in relevant emerging areas.
- Review guidelines, standards and protocols to ensure they provide those working in CF with the most up-to-date guidance on care delivery.
- Regularly review role descriptions and job plans for those working in CF to ensure they reflect changes in work and activities delivered.
- Enhance psychological and social support available to meet increasing need.
- Ensure adult CF services are resourced to respond to a population that is increasing in size and complexity.
- Encourage robust succession planning in CF teams and support training for the next generation.
- Enhance collaboration between CF teams and other providers.

Introduction

At a time of significant transformation and change in CF care, the cystic fibrosis (CF) workforce survey allows us to capture the perspectives of those working in CF care across the UK to help us understand how CF work is changing for them. We are grateful for the support of CF professional interest groups in developing and disseminating the survey, and for every CF professional who took the time to share their views.

This report provides a summary of the key insights from the first survey cycle. It reveals a field adapting rapidly to transformative modulator therapies, with workload for CF teams shifting from inpatient and acute to more holistic and preventative care, often delivered remotely or in the community. With repeating survey cycles every three years, future findings will provide important information to help us understand how CF professionals workload and experiences may change over time.

About the survey

The CF workforce survey questions were developed with input from Cystic Fibrosis Trusts Clinical Advisory Group (CAG) and Quality Improvement (QI) working group, which is made up of people with CF, family members and CF professionals. The survey was also tested with a group of volunteers from different disciplines working in CF, and adapted according to their feedback, before it was launched.

From 12 March to 18 April 2025, CF professionals across the UK could complete the survey online. It was promoted through CF professional interest groups, as well as Cystic Fibrosis Trust, via emails, newsletters, and at relevant events. The survey asked CF professionals to reflect on changes in their workload compared to five years ago (since early 2020), which saw the introduction of modulator therapies as well as different approaches to care delivery due to the COVID-19 pandemic. Other survey questions explored views on challenges encountered in CF work, career, training and resources, as well as professionals future outlook on CF care. Not all data collected in the survey are presented within this report.

In 2028, the workforce survey will be repeated to help us explore how professionals workload and experiences change with time. While we will aim to provide longitudinal information that can be compared over time, the survey process is iterative, and some questions may be refined, replaced or added in future.

About this report

This report provides an overview of key findings from the first cycle of our CF workforce survey, split by paediatric and adult care, where appropriate. Quantitative survey responses were analysed descriptively. Survey respondents were allowed to skip questions where they did not feel well placed to answer, or something did not apply to them (these are recorded as 'unknown' in figures within this report). The number of responses that were included in the analyses, and responses that were excluded, are provided for reference alongside each figure.

Where respondents provided free text comments within survey responses, these were analysed thematically. Insights from free text comments are summarised, and the report contains example anonymised quotes to illustrate themes and findings, where relevant.

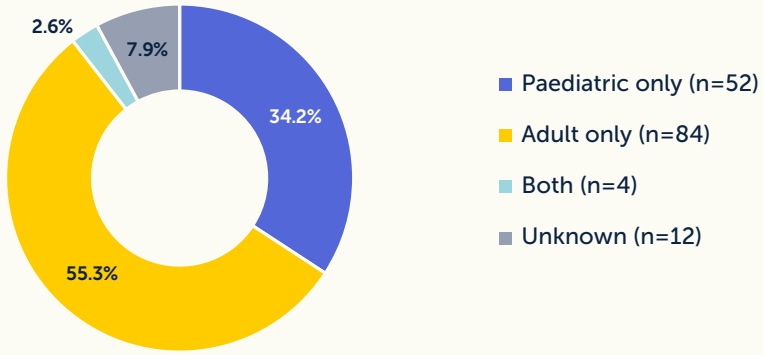
Survey sample

The insights in this report are based on responses from CF professionals working in more than 57 different CF centres and clinics across the UK. Of 58 centres, at least 45 (79%) are represented within the sample, with additional respondents from 12 different clinic sites, which are usually linked to a larger centre in a CF network. Forty-four respondents (29%) chose not to disclose their centre/clinic. It is therefore likely that more CF services are represented within the sample.

A third of respondents (n=50; 33%) were from a nursing background. Dietetics, medicine, physiotherapy, pharmacy, and psychology had between 10 and 26 respondents (7%–17%) each. Nine respondents (6%) came from other professions, including social work, occupational therapy and youth work. Twelve respondents' profession (8%) is unknown.

Figure 1: Population cared for by survey respondents

All survey respondents included (n=152).

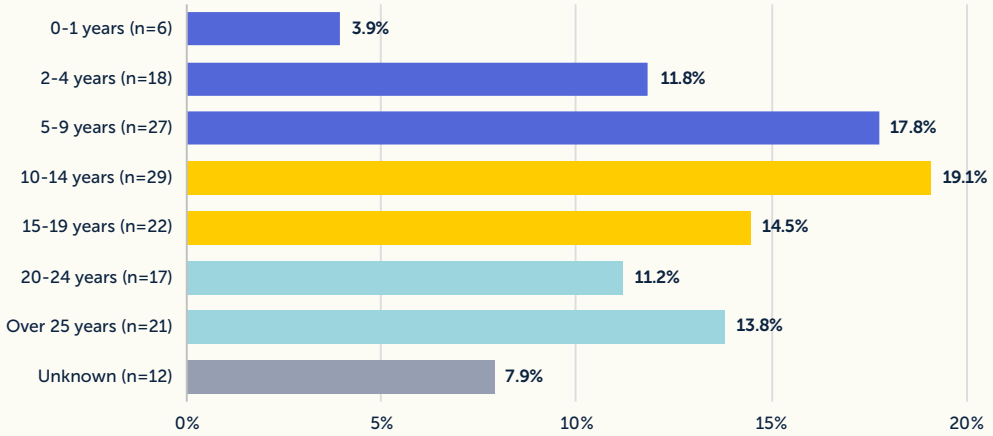


A third of respondents (n=52; 34.2%) worked in paediatric care only, 84 respondents (55.3%) worked exclusively in adult care, and four (2.6%) worked across both settings[1] (Figure 1). Twelve respondents did not disclose their work setting.

The sample includes CF professionals working at grades from Band 5 to 8c[2] or at consultant level, with varying lengths of experience working professionally in CF.

Figure 2: Experience working professionally in CF

All survey respondents included (n=152).



A third of respondents (33.5%) had been working professionally in CF for less than 10 years, with another third (33.6%) bringing 10–19 years of experience, while a quarter (25.0%) had worked in CF for 20 or more years (Figure 2).

1 The four respondents who worked across settings confirmed their main workload was in adult care and are therefore included within the adult sample in split analyses presented in this report.

2 NHS Agenda for Change banding

The level of experience working in CF differed slightly between paediatric and adult care respondents. A larger proportion of those working in paediatrics reported 20 or more years of experience (34.6%) compared to respondents from adult care (22.7%).

Many CF professionals in the survey worked part-time and/or were only partially contracted to work in CF, while also contracted to cover other disciplines. Many respondents reported having expanded roles and responsibilities, including MDT lead roles, prescribing roles, and involvement in outpatient care beyond MDT clinics.

Limitations

Our sample size of 152 CF professionals represents a relatively small proportion (<10%) of those working in CF in the UK. While we achieved good geographical spread of respondents, the data set usually includes only one or two respondents from any individual service. It is therefore not possible to draw any service-level conclusions, nor to share service-level insights.

As the survey sought to understand the perspectives of CF professionals, the data presented are subjective and based on experiences of our respondents. Others' views on CF care may be different. However, there was significant overlap in feedback shared by respondents in the survey from all professions and locations, as well as previous intelligence received by Cystic Fibrosis Trust, and published literature.[3,4,5]

Nurses are overrepresented within our sample. While nurses are one of the largest professional groups working in CF, other professions in CF multidisciplinary teams (MDTs) are likely underrepresented in our data. The results may therefore reflect nurses' experiences more strongly than those of other professions.

Given the subjectiveness of the data, changes in workload presented in this report cannot be quantified in terms of changes in hours spent. Rather, the proportions of respondents who perceived a change in workload are shown. Where large proportions of respondents reported a change in the same direction, it is likely that overall workload in the respective area of activity has changed. In contrast, it is likely overall workload has not significantly changed where large proportions of respondents felt their workload had stayed the same, and/or where similar proportions perceived a decrease as did an increase. However, in such cases it may be that workload in that area of activity fluctuates at individual or profession level.

To explore changes in workload, respondents were asked to look back five years. Recalling workload in early 2020 may be difficult for some respondents but this timeframe was deemed preferable for the first survey cycle as it would allow comparison to workload before significant changes due to the introduction of modulator therapies, as well as the expansion of virtual provision accelerated by the COVID-19 pandemic. In future cycles, we will look at workload changes over three years. As this was the first time we ran our workforce survey, we are looking to make improvements before re-running it in 2028. The data from this cycle, as well as feedback from respondents in 2025, will help inform these amendments.

3 Diener BL, Huertero F, Stables-Carney T, Hoelzer M, Kier C. A new era in cystic fibrosis care: always changing and adapting. Curr Opin Pediatr. 2023

4 Southern KW, Burgel PR, Castellani C, De Boeck K, Davies JC, Dunlevy F, Fajac I, Gramegna A, Lammertyn E, Middleton PG, Ratjen F, van Koningsbruggen-Rietschel S. Standards for the care of people with cystic fibrosis (CF). J Cyst Fibros. 2023

5 Goetz DM, Brown RF, Filigno SS, Bichl SL, Nelson AL, Merlo CA, Juel R, Lomas P, Hempstead SE, Tran Q, Brown AW, Flume PA; CFF Care Model Committee. Cystic fibrosis foundation position paper: Redefining the CF care model. J Cyst Fibros. 2024

Section 1
Evolving workload

1. What has changed in CF care?

The survey sought to capture CF professionals' reflections on changes in CF care beyond the introduction of modulators and increasing virtual provision.

Survey question: In the last 5 years, what do you think are the main changes in CF care, aside from modulators and expansion of virtual provision?

Figure 3a: Word cloud of reflections on what changed in paediatric care. Based on comments from 50 CF professionals working in paediatric care

Figure 3b: Word cloud of reflections on what changed in adult care. Based on comments from 85 CF professionals working in adult care

There was overlap between changes seen by respondents working in paediatric and adult CF care, but also some differences. In both settings, respondents reflected on transformation driven by new treatments, which have had significant downstream effects on population needs and care delivery. Several CF professionals acknowledged the positive impact of modulator therapies for many people with CF within their responses.

> "Such a great time to be working in CF seeing the effect of modulators."
> **– Dietitian, adult care**
>
> "Many patients are more well and living healthier, fuller lives than in the past. There is more focus on preventative care, certainly in paediatrics."
> **– Dietitian, paediatric care**
>
> "Seeing patients enjoying increasingly normal lives including education, employment, and starting their own families.""**– Doctor, adult care**

Most respondents had seen significant reductions in acute care needs, inpatient admissions and IV antibiotic use, and felt that care was moving towards more outpatient, virtual, and remote contact.

> "Change in balance between inpatient and outpatient work, with more virtual work."" – **Doctor, adult care**
>
> "Less inpatient care, much more outpatient reviews, home visits and virtual/ telephone calls."" – **Physiotherapist, adult care**
>
> "Reduction in IV antibiotic therapy, reduction in inpatient stays, increase in outpatient care."" – **Nurse, paediatric care**

Respondents noted there is less respiratory symptom burden for many, with the focus shifting to non-respiratory issues, including CF diabetes, gastrointestinal problems, weight management, and psychosocial complexities including mental health and neurodiversity.

> '[We are] supporting patients with new emerging co-morbidities, such as overweight and obesity, lipids, psychosocial issues that impact on their health." – **Dietitian, adult care**
>
> "Obviously modulators have had a massive impact on the care required. In paediatrics we have seen a huge increase in social and psychological needs." – **Nurse, paediatric care**
>
> "People are now more focussed on symptoms other than respiratory, e.g. gastro and mental health. I sometimes feel more like a GP than a CF specialist and get called for lots of non-CF related issues." – **Other CF professional, adult care**
>
> "[There] seems to be more general awareness of mental health and emotional wellbeing issues within CF care (reflecting greater awareness about this in general probably). Much more reporting of potential neurodivergence and work related to this." – **Clinical psychologist, adult care**
>
> "We have seen more cancer diagnoses, renal issues with post-transplant patients, end of life care, and supporting children of the patient, much more nurse- led clinics, less consultant input." – **Nurse, adult care**

Several respondents highlighted that engagement with CF care had changed, which could be difficult to manage, impact workload, and result in clinical setbacks. Respondents shared that improved health can change attitudes towards medical care and treatments. Additionally, many people with CF have new life commitments, such as family, education, and work, leaving less time for treatments and medical appointments.

> "Adherence to treatment and the changes in health following modulators features heavily in our clinics, with patients reducing treatments as feeling better, or doing less physio/none as feeling better. However, this has resulted in falls in lung function and then required restarting of certain aspects of their care." – **Nurse, paediatric care**
>
> "Patients have less available time to engage in support due to life commitments e.g. work, family. This is requiring that we as a team need to consider alternative means of supporting our patients." – **Dietitian, adult care**

Other changes mentioned by survey respondents included changes to resourcing and commissioning, staffing issues, medication shortages, and evolving MDT roles.

> "NHS England being disbanded, commissioning changes, staffing shortages, being pulled to help to cover shortfalls in other services." **– Physiotherapist, adult care**
>
> "A greater feeling of medicine insecurity - varied access to nebulisers and inhaled medications. Issues with Creon." **– Physiotherapist, adult care**
>
> "Reduction in medical staff cover, more reliance on MDT to complete tasks previously done by doctors (notably nurses, pharmacists, dietitians)." **– Pharmacist, adult care**

While there was a lot of overlap between changes seen by staff working in paediatric and adult CF care, there were some differences in experiences depending on setting. Specifically, among respondents from adult care, a common observation was that the CF population is growing and ageing, leading to new support needs around fertility, pregnancy, and menopause, as well as increased complexity with comorbidities such as cardiovascular disease, cancer, and other conditions of older age.

> "Older patients [are] becoming more complex, with some healthcare needs being more problematic than their CF." **– Dietitian, adult care**
>
> "We are beginning to see more issues commonly associated with older adulthood, there has also been an increase in cardiometabolic disorders such as strokes. The need for fertility and maternity support has also increased greatly." **– Nurse, adult care**

CF professionals report significant changes in population needs and CF care, mainly driven by modulator therapies, but wide-ranging in their impact:

- Care delivery is shifting away from acute and inpatient care to more outpatient, remote, and preventative models, with an emphasis on long-term management and quality of life.
- Population needs are diversifying. Some patients still require mainly respiratory and acute care, while many others now present with a wider range of issues, including gastrointestinal symptoms, CF diabetes, mental health problems, and neurodiversity.
- Complexity is increasing, with new demands arising particularly in adult care around fertility, pregnancy, menopause, and conditions of ageing.

2. How is workload evolving?

Given the transformational impact of new therapies, and novel approaches to care delivery, the survey explored perceived changes in workload across 19 areas as outlined in the Standards of Care for CF.[6] This included clinical activities, both patient- and non-patient-facing, and non-clinical activities, such as governance and personal development.

Survey question: Has the workload changed compared to early 2020?

Figure 4a: Perceived workload changes in paediatric CF care

Based on n=49 respondents who work in paediatric CF care, excl. 3 respondents who did not yet work in CF in 2020; proportions shown are out of those to whom an area of activity was relevant and ordered by perceived decrease (respondent number for each area is shown in y-axis)

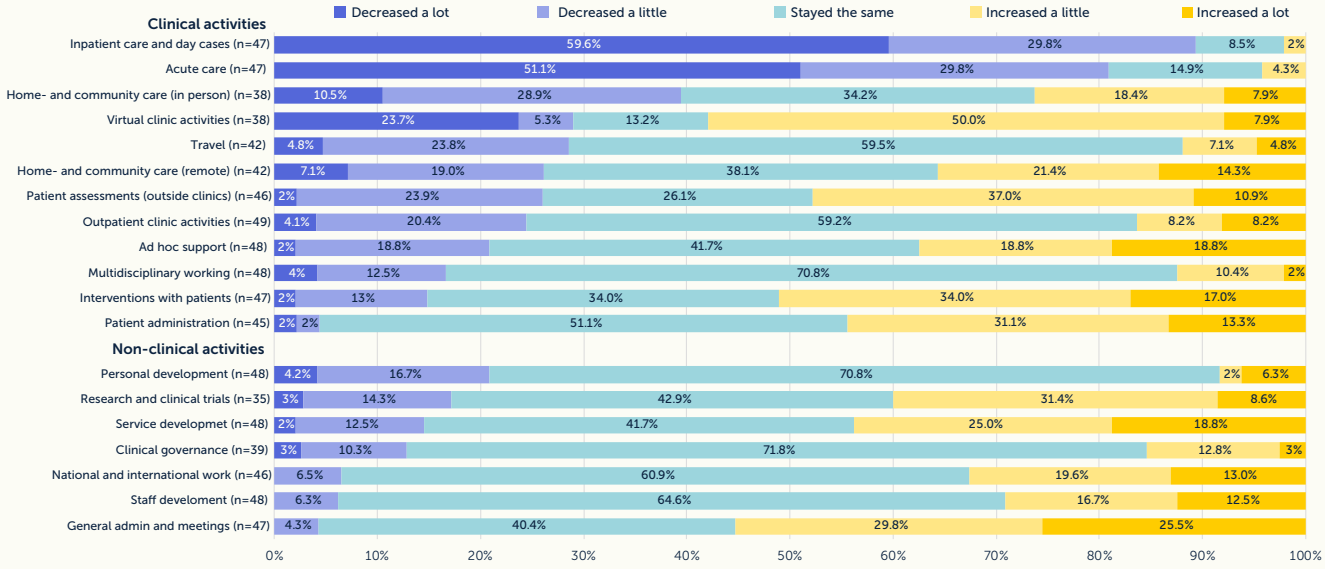
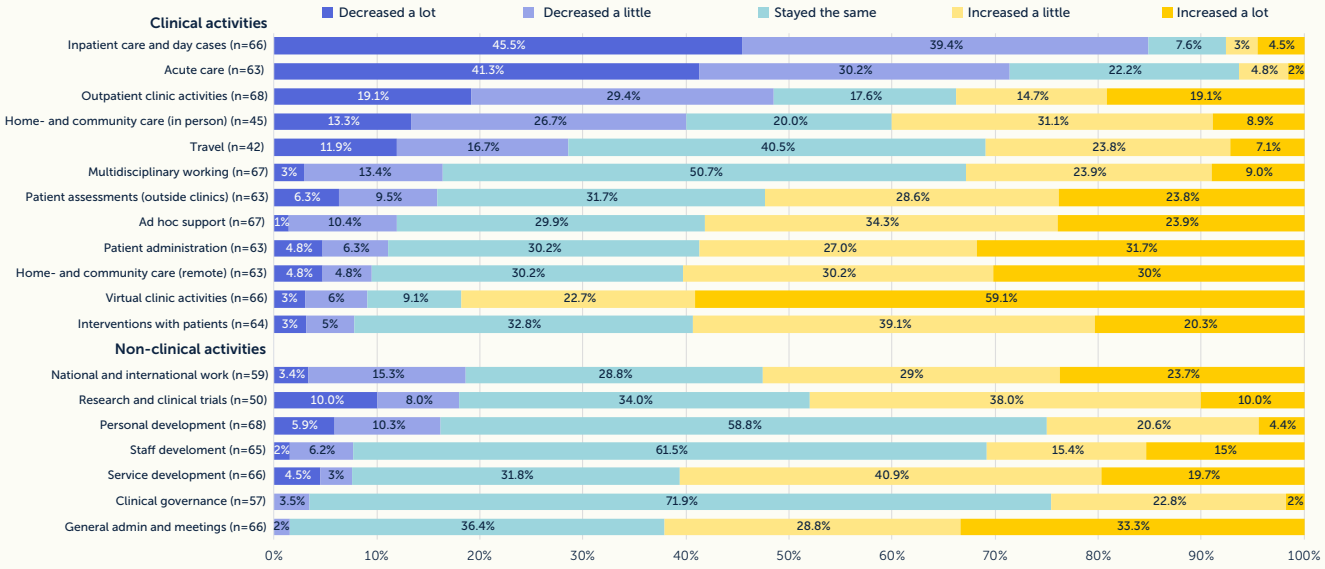


Figure 4b: Perceived workload changes in adult CF care

Based on n=68 respondents who work in adult CF care, excl. 20 respondents who did not yet work in CF in 2020; proportions shown are out of those to whom an area of activity was relevant and ordered by perceived decrease (respondent number for each area is shown in y-axis)



Overall workload for many CF professionals is evolving, rather than reducing.

6 Cystic Fibrosis Trust, Standards for the clinical care of children and adults with cystic fibrosis in the UK, Third edition (August 2024)

Clinical activities

In our workforce survey, CF professionals report a shift, rather than an overall reduction, in clinical CF workload. In line with NHS statistics and the UK CF Registry,[7] which show reduced rates of admissions and IV days in recent years, 87% and 76% of CF professionals in our survey reported reductions in inpatient care and day cases, and acute care, respectively. This was seen across paediatric and adult care settings (Figure 4a and b). However, reflections shared by respondents highlight that there can be fluctuations in inpatient numbers, and many noted that complexity of those needing admission had not reduced.

> "The service has shifted slightly away from inpatient care and more towards outpatient management (though we still do experience periods where there are a significant number of inpatients admitted to the ward). We are also seeing fewer chest exacerbations requiring treatment with IV antibiotics." **– Pharmacist, adult care**
>
> "The inpatient care has significantly reduced although we still have babies with meconium ileus which can take significant time." **– Dietitian, paediatric care**
>
> "Big move to outpatient services but increase in complex inpatient CF over time. We now have a much bigger population in our adult clinic than we would have had a few years ago and the complexity continues to rise with more diabetes etc." **– Doctor, adult care**
>
> "Inpatient caseload decreased quite a lot post-modulator therapies, but last winter we have seen an increase in admissions. Admissions also seem to be more complex and take longer to sort." **– Dietitian, adult care**

Slightly larger proportions of respondents also reported a reduction in outpatient clinic workload than reported an increase. However, for many respondents, outpatient work had stayed the same (full sample n=125: 38% decrease, 36% stayed the same, 26% increase). Some respondents specifically remarked on the drawbacks of virtual clinics in responses.

> "Greater access to virtual appointment has reduced F2F workload in outpatients, but not always desirable. Some individuals prone to overuse virtual contact and avoid coming to a physical clinic once the option is known to them." **– Doctor, adult care**
>
> "It can be challenging to support patients when they are attending face-to-face less frequently. Additionally, increased outpatient activity has impacted on capacity even taking into account the reduction in inpatient activity." **– Dietitian, adult care**

Decreases in outpatient clinic workload were experienced by larger proportions of respondents in adult care, where 49% reported a reduction since early 2020 (Figure 4b). This is likely due to the increased availability of virtual clinic options, which are more frequently used in adult CF care as they can be problematic in paediatric settings.

> "Due to the changing nature of health for most people with CF, where they are generally more well, in our adult service we decided to move to a model where outpatient care was provided on a 'needs basis' and developed a local assessment tool." **– Dietitian, adult care**
>
> "F2F clinics decreased/stopped for a short time during the COVID pandemic and all clinics were virtual. Following the COVID pandemic, we run no virtual clinics, all of our clinics are F2F again." **– Nurse, paediatric care**

7 Cystic Fibrosis Trust, UK CF Registry 2023 Annual Data Report (October 2024)

For some of the other activities linked to CF clinical care, specifically in-person homecare, travel, and MDT working, workload fluctuated at individual levels. However, overall workload across our sample did not appear to have changed significantly, as large proportions in both settings reported workload to have stayed the same and/or proportions reporting increases and decreases were similar (Figure 4a and b).

However, in several other areas of activity many respondents perceived that their workload had increased. Some of this differed by setting. Virtual clinic workload had reportedly increased in paediatric and adult settings, but a much larger proportion of respondents from adult care (82%) perceived their workload in this area had increased compared to respondents from paediatric care (58%) (Figure 4a and b).

> "The balance of work has shifted towards outpatient and virtual work with further emphasis on complication monitoring with the introduction of colonoscopies and an ageing group of CF adults." – **Doctor, adult care**
>
> "Virtual appointments have been a real boon, however they create their own issues and can be more time consuming to fit around face to face appointments and [it] can be difficult to do a full assessment." – **Nurse, adult care**
>
> "There has been a trend away from inpatients and more to care in the community. This type of work does take more time, as does arranging for appointments to be set up virtually and dealing with technical issues around this." – **Physiotherapist, paediatric care**

Similarly, patient assessment work, patient administration, intervention activities, and ad-hoc support workload had increased in both settings. This was again experienced by larger proportions of respondents from adult care (Figure 4b). Additionally, remote homecare workload had reportedly increased for many in adult care but appeared to have remained relatively stable across respondents from paediatric care.

> "Clinics are busier, as we are often having to do induced sputum tests since patients rarely bring up sputum on Kaftrio." – **Physiotherapist, adult care**
>
> "I find I am doing a lot more admin than I used to pre-pandemic, particularly associated with altering clinic appointments, despite often asking patients to contact the appointments department themselves. Unfortunately, often patients can't get through despite calling." – **Nurse, adult care**
>
> "There has certainly been an increase in support over phone/email or through MDT meetings/school meetings. There have been more mental health issues, involving more teams and specialist help, as well as 'cost of living' support required." – **Nurse, paediatric care**

Non-clinical activities

Non-clinical activities are vital to support staff, teams and services. These activities include general administration, governance, development, and research. Only small proportions of respondents reported decreases in non-clinical workload over the last five years. Instead, many perceived non-clinical workload to have stayed the same or to have increased. For all areas of non-clinical activities included in the survey, larger proportions of CF professionals from adult care perceived increases than decreases. Many respondents specifically noted that they would like more time for non-clinical aspects of their roles.

> "Some areas I would like to have time to do more – e.g. service development/QI, work on national/international groups... but I struggle to do as much as I would like with the current clinical workload." – **Doctor, paediatric care**

General administrative workload was the area of non-clinical activity where the largest proportions of respondents perceived their workload had increased (full sample n=116: 2.6% decrease, 39% stayed the same, 59% increase). This was similar across adult and paediatric care, with 62% and 55% reporting increases in general admin work, respectively (Figure 4a and b).

> "General administrative tasks take up much more of my time. This is partly because children are spending less time in clinic and as inpatients, so need their monitoring arranged at other times. Also, because the NHS systems are increasingly time consuming, with additional asks from business managers, who don't seem to understand the needs of the specialty." – **Nurse, paediatric care**
>
> "Pre 2020 my team had been very stable, not so much since then. I've struggled to fit in admin tasks due to lack of staff and have had to work a lot of unpaid overtime." – **Physiotherapist, adult care**
>
> "We've had a new IT system for the last few years which has made many of the admin tasks a lot easier, but there continues to be a lot of training needs, as people still haven't fully learned all the functionality available. This can create more work in the short term, even though we're supposed to be more efficient." – **Nurse, adult care**

Many respondents in both settings also perceived the need for service development work to have increased, particularly given the impact of modulators and evolving models of CF care. Increasing service development workload was reported by a larger proportion of respondents from adult care (61%) compared to paediatric care (44%) (Figure 4a and b).

> "Service development / QI workload has increased hugely to try and respond to changes in CF care and challenges at our centre in terms of loss of estate post-COVID. Time to complete research and act on audit is challenging." – **Physiotherapist, adult care**
>
> "Service development aspect of role requiring more planning and time to ensure child and family needs are being met." – **Clinical psychologist, paediatric care**

Research, clinical trial, guideline, and committee work can vary by role, seniority, capacity, and or interests. This workload can also fluctuate for individuals over time, for example when someone begins or completes a training course or research project. In both care settings, more respondents perceived research/trial activity and national/international work on guidelines and committees to have increased, rather than decreased. However, many also reported this had remained relatively stable for them.

> Being awarded an academic fellowship has enabled me to have the time to deliver more quality improvement, research and undertake national work." **– Dietitian, adult care**
>
> "I would like to be involved in specialist interest groups and committees etc. but struggle to manage my workload as it is sometimes." **– Other profession, paediatric care**
>
> "Whilst the opportunities to get involved in research have increased, the time I have for research is now zero. It is not seen as a priority and managers simply want me to do the basic tasks which is not fulfilling as a job." **– Pharmacist, adult care**
>
> "I have never had time in the job plan for clinical CF research, so this has not changed. The number of trials has reduced, but the complexity has increased." **– Doctor, adult care**

Staff development workload appeared to have stayed the same for many, but had increased for some, which was true across settings (full sample n=117: 7.7% decrease, 61% stayed the same, 32% increase). Increasing staff development workload may in part be driven by lower retention and high staff turnover. It may also be linked to changing models of care and emerging population needs that necessitate further training and education of staff who care for people with CF, including ward staff.

> "Since COVID we have had a higher turnover of staff. [It's] much harder with recruitment to get cover, so then having to appoint more junior staff, who take longer to train and require more supervision." **– Dietitian, adult care**
>
> "Generally, there has been a significantly higher staff turnover since 2020. On some occasions staff have changed three times within a year, which is not ideal for patient care and significantly increases training time." **– Dietitian, paediatric care**

Clinical governance and personal development workload appeared to have remained comparatively stable for respondents from paediatric settings (Figure 4a). Among those working in adult care, slightly larger proportions reported increases in these areas than decreases, but over half of respondents also confirmed these stayed the same (Figure 4b).

> "Non-clinical work has remained the same overall. Still managing to meet CPD requirements although there is some pressure from outside of the CF team when applying for courses, but generally well supported." **– Nurse, paediatric care**
>
> "It feels like governance is a bit 'helicopter'. We often are left alone for long periods, often not feeling supported with our own concerns, then suddenly an issue eats up time and resources." **– Nurse, adult care**

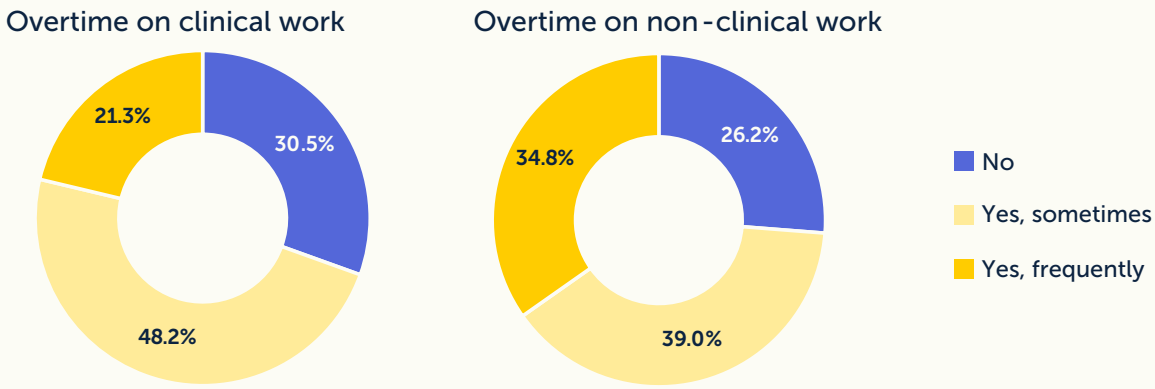
3. Time constraints

As a result of increasing workload, CF professionals may struggle to deliver all aspects of their roles within the hours allocated. To explore this, the survey specifically asked if staff found themselves working overtime on clinical or non-clinical aspects of CF work.

Survey question: Do you find yourself working more than your contracted hours on clinical or non-clinical CF work?

Figure 5a and 5b: Proportion of respondents working more than contracted hours

Based on n=141 responses, excl. 11 skipped



Over two thirds of respondents reported working more than their contracted hours on clinical CF work (n=98, 70%), rising slightly to three quarters (n=104, 74%) for non-clinical work. This is likely driven by increasing virtual, remote, intervention and assessment workload, as well as administrative burden (Section 1.1; Figure 4a and b).

Slightly higher proportions of CF professionals from adult care reported working extra hours, both clinically and non-clinically. Among survey respondents from adult care, 75% reported spending more than their contracted hours on clinical CF work, compared to 61% in children's services. For non-clinical activities, 77% of respondents from adult care and 69% from paediatric care reported working longer than their contracted hours. This aligns with perceived increases in workload reported across many areas of activity by our adult respondents as described in Section 1.2.

70% of respondents reported working more than their contracted hours on clinical CF work, rising to **74%** for non-clinical work.

Section 2
Challenges

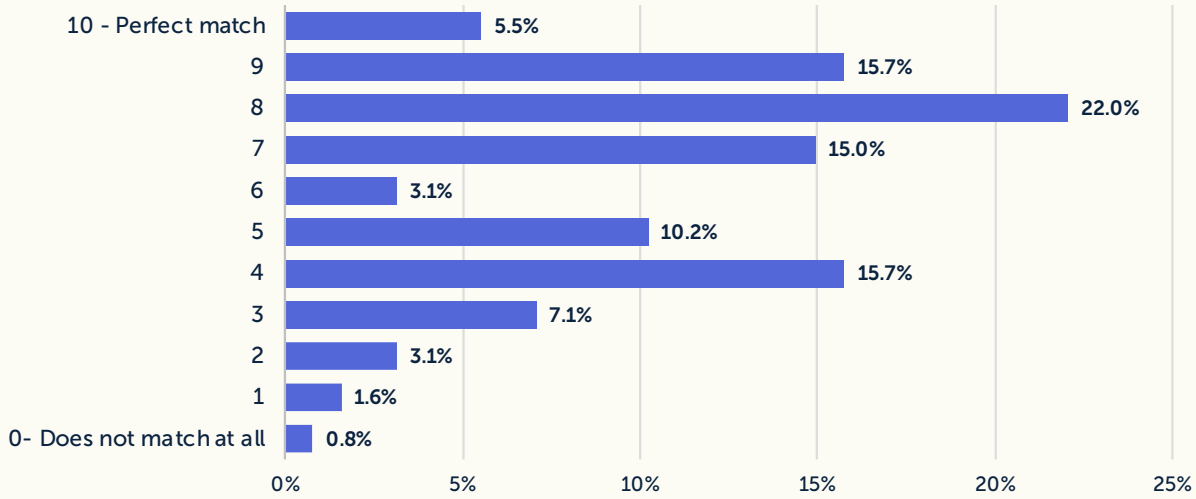
1. Diverging roles

Given the wide-ranging changes in CF care described in Section 1, day-to-day activities for those working in CF teams may start to diverge from what was outlined in their original role description. To explore this, our survey asked respondents to rate how closely their current work matched their original job description.

Survey question: To what degree does the day-to-day work you do in CF match your job description?

Figure 6: Perceived match between role description and day-to-day work

Based on n=127 responses, excl. 25 skipped



Overall, 58% of survey respondents (74 of 127) gave a rating of 7 or above, indicating an acceptable match between their current work in CF and their role description, but only 5.5% (n=7) deemed it a perfect match (Figure 6). A slightly larger proportion of respondents from paediatric care gave ratings of 7 or above, compared to adult care (65% versus 54%).

Twenty-nine per cent (37 of 127) of our respondents provided a score between four and six, indicating that there were some discrepancies between their day-to-day work and their original job description. Thirteen per cent (16 of 127) felt there was a poor match, giving a rating of three or lower. Larger proportions of pharmacists, psychosocial staff and physiotherapists provided a low score compared to doctors, nurses and dietitians.

These findings indicate that some descriptions, as well as job plans, for roles in CF MDTs may need to be reviewed and amended to better reflect activities delivered now.

13% of our respondents gave a low rating for the match between day-to-day work and their original role description, suggesting that, for some professionals in CF, day-to-day activities delivered are diverging significantly from original role descriptions.

2. Staffing and resourcing

Forty-three per cent of CF professionals in our survey (65 of 152) perceived staffing to be a challenge. Survey respondents highlighted that workforce pressures within healthcare generally are impacting staff recruitment, retention and capacity in CF teams, as previously also evidenced by our annual UK CF service resourcing report.[8]

> "It is increasingly difficult to replace posts when MDT members leave due to huge financial constraints within the NHS Trust." – **Doctor, adult care**
>
> "Poor support from respiratory management at our Trust has led to two of our longest serving consultants leaving. We haven't managed to recruit to their posts." – **Physiotherapist, adult care**

While this was true across professions within CF MDTs, survey respondents specifically highlighted gaps in availability of social workers as a challenge. This aligns with findings from our UK CF service resourcing report and our patient-experience surveys,[9] which have highlighted gaps in psychosocial provision.

> "Increased social issues and we do not have a social worker. A lot of patients are adapting to life with Kaftrio, are feeling better, and having benefits taken away. Getting asked to write a lot of letters to support housing, PIP applications, funding for household appliances and holidays, etc." – **Other profession, adult care**
>
> "Not having a social worker has impacted us, especially with patients applying for PIP but meeting fewer of the eligibility criteria. The impact of social media and some patients becoming influencers and ill-advising the patient community has caused some issues." – **Nurse, adult care**

Due to NHS-wide staffing shortages, more than a quarter of our respondents (27%, 41 of 152) confirmed that they were being asked to cover other conditions or departments, which could be challenging.

> "We cover for general respiratory and infectious disease –short staffing in other departments has a big impact." – **Dietitian, adult care**
>
> "Being asked to cover wards and other services particularly through winter, leaving the CF service uncovered." – **Nurse, paediatric care**
>
> "Our bronchiectasis patients have no nebuliser or IV service. CF team constantly asked to support these complex patients as no one else can. My role directly affected when doctors are short as our nurses are not prescribers." – **Pharmacist, adult care**

Some survey respondents worried that perceptions of improvements in health for those living with CF post-modulators, and reductions in acute and inpatient workload, might lead to reduced staffing or resources for CF care in future. They felt this could risk deterioration in service quality.

> "Main issue is other professionals not working in CF thinking it is 'all fixed' as patients not on the ward and not recognising: the workload has just changed not gone away." – **Doctor, paediatric care**
>
> "Time for non-CF work is becoming an increasing concern, as we are often perceived as having more 'free time' due to the reduced inpatient demands." – **Pharmacist, adult care**

8 Cystic Fibrosis Trust, UK CF Service Resourcing 2022-2024 (April 2025)

9 Cystic Fibrosis Trust, Paediatric/Adult patient experience reports; available from cysticfibrosis.org.uk/the-work-we-do/quality-improvement

Succession planning was a particular concern, with respondents from different professions mentioning this as a challenge.

> "Succession planning is a big issue that needs addressing, especially in view of how CF is changing." – **Nurse, adult care**
>
> "Bureaucracy and financial limits stifles succession planning." – **Other profession, paediatric care**
>
> "It is sometimes a challenge to recruit into CF care. I love it and think it's an incredibly rewarding role to have, but I think people see it as a 'niche' role and aren't quite sure what it will entail." – **Pharmacist, adult care**

Professional development and career progression was another area discussed by respondents, who worried about staff becoming deskilled and highlighted resourcing concerns around funding for training and development in CF. Fifty-nine per cent (90 of 152) and 38% (57 of 152) of our respondents confirmed that funding and time constraints limited their ability to access formal training, respectively.

> "Our region currently has a complete ban on study leave for all due to financial constraints." – **Dietitian, adult care**
>
> "Care needs are changing but there is no clarity on what new skills and competences are needed." – **Other profession, adult care**

3. Change and uncertainty

Adapting to change

Adapting to change and new uncertainties was perceived as a challenge by 56% of our survey respondents (85 of 152). Some reflected specifically on the impact of changing models of care on those working in CF.

> "Supporting MDT and associated new complexities that have come with the changes to CF care, and its impact on how the MDT needs to function." – **Clinical Psychologist, adult care**
>
> "Supporting changes in care which may require more long-term behavioural changes with limited time." – **Dietitian, adult care**

Adapting to new technologies

Forty-four percent of our respondents (67 of 152) felt the digitalisation of healthcare generally, including new IT systems, virtual clinics and wards, as well as remote monitoring technologies, had introduced challenges.

> "Still adapting to a relatively new IT system that hasnt been set up to meet the needs of our service. Ongoing discussions in relation to adaptations required." – **Other profession, adult care**
>
> "The hospital is having a complete change in IT systems." – **Nurse, paediatric care**

4. Care delivery

Medicine supplies

Sixty-six per cent of our survey respondents (101 of 152) confirmed that medicine supply shortages had been a major challenge for them in their CF work recently, with many specifically mentioning pancreatic-enzyme replacement therapy (PERT)/Creon shortages.

> "Medication shortages are a huge issue. It feels like every week a new medication is unavailable." – **Nurse, adult care**
>
> "Creon shortages created increased workload and provoked a lot of anxiety requiring support." – **Nurse, paediatric care**
>
> "Medicine and nebuliser device supply problems are taking up a lot of time." – **Physiotherapist, adult care**

Physical space

Several respondents mentioned issues with physical space in free text comments. Some teams reported CF wards being closed or converted to general respiratory wards, others struggled with clinic rooms and space to deliver outpatient care.

> "We've had to do a lot of adaptations since the pandemic, and our physical space has been severely curtailed ever since." – **Nurse, adult care**
>
> "Our main problem since COVID is the lack of space. One of our clinics has been cut as other specialities are using the space at that time. Due to the closure of our inpatient ward and the movement of CF inpatients to another hospital we have to travel between hospitals to deliver CF care." – **Physiotherapist, adult care**

General support

Respondents from several different professions shared that they found themselves supporting people with CF with issues unrelated to CF for a number of reasons. This was a challenge experienced by 57% of respondents in our survey (86 of 152).

> "We have a significantly larger patient group than a few years ago, so clinic capacity is increasingly a concern. We are also spending a lot of time dealing with issues unrelated to CF due to difficulty accessing primary care." – **Nurse, adult care**
>
> "Significant safeguarding workload with very little support. Supporting families with issues unrelated to CF (such as relationship breakdown/financial issues/ mental health, neurodivergence), due to a lack of external services/long waiting lists etc." – **Other profession, paediatric care**
>
> "Often patients request support with non-CF morbidities – e.g. MSK issues - can offer advice but not specialist in area." – **Physiotherapist, adult care**

Administrative burden

In line with reports of increasing administrative workload (Section 1), 40% of respondents (61 of 152) felt that increasing administrative burden was a challenge.

> "Introduction of a new electronic patient records system has led to more admin time." – **Clinical psychologist, adult care**
>
> "High amount of admin tasks linked to lack of admin support from professional department (dietetics) rather than CF." – **Dietitian, adult care**
>
> "Lots more DNAs [Did Not Attend] to appointments, admin increased to rebook." – **Undeclared profession/setting**

Professionals working in CF face a number of challenges:

- Staffing and resourcing issues, which also affect the wider NHS, are impacting CF teams in terms of capacity, recruitment and succession planning, as well as funding and time for training and development.
- Changes in models of care, funding arrangements, and technologies require CF professionals to develop new skills, and to rapidly adapt behaviours and practice.
- Care delivery was impacted by medicine supply shortages, limitations on physical spaces available to CF teams, as well as new and increasing demands on CF professionals.

Despite the numerous challenges shared by respondents, CF professionals remained committed to delivering high quality care and shared their priorities and ideas for the future, which are summarised in Section 3 below.

Section 3
Outlook and ideas for the future

As CF care and work is evolving, it is important to capture CF professionals' outlook, as well as their ideas and priorities. Our survey explored optimism about the future, confidence in ability to adapt, as well as views and ideas to maintain and improve quality of CF care.

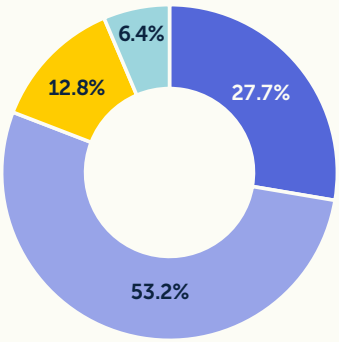
1. Outlook

Survey question: How optimistic do you feel about the future of CF care generally?

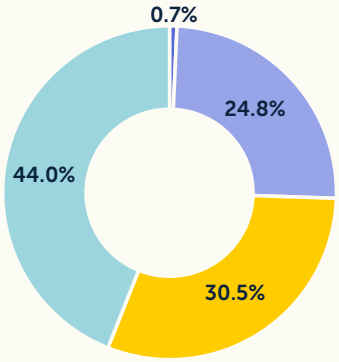
Figure 7a and 7b: Optimism about the future of care generally and funding for care

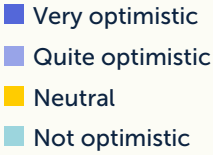
Based on n=141 responses, excl. 11 skipped

Future of CF care generally



Future of funding for CF care



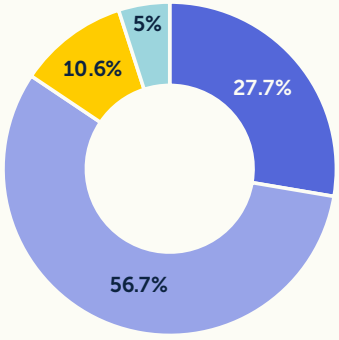


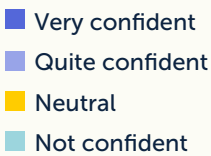
The vast majority of respondents remained very or quite optimistic about the future of CF care generally (81%; 114 of 141), with only nine professionals (6%) not feeling optimistic. However, respondents were less optimistic about the future of funding for CF care, where sixty-two respondents (44%) did not feel optimistic, and 43 respondents (31%) felt neutral.

Survey question: How confident do you feel about your team's ability to respond to changes in the needs of the CF community?

Figure 8: Confidence in team's ability to adapt to changes in needs

Based on n=141 responses, excl. 11 skipped





In line with optimism about the future of CF care generally, CF professionals in the survey also remained confident in their team's ability to adapt to changes in needs, with 84% (119 of 141) stating they were very or quite confident.

Over 80% of our respondents remained optimistic about the future of CF care and their teams' ability to adapt, though they were less optimistic about future funding.

2. Priorities

The survey asked CF professionals what they felt was most important when it came to improving CF care.

Survey question: What is your top priority for improving CF care?

Over 90% of our respondents (137 of 152) gave an answer. Priorities were similar among respondents from paediatric and adult settings. Comments could broadly be split into two themes: one focused on patient-facing care delivery and engagement, the other on staff development and ways of working.

Care delivery and patient engagement

A key priority for many CF professionals in our survey was ensuring equity and access to care and effective treatments. Importantly, this included continued efforts to find treatments for those who cannot benefit from currently available modulator therapies.

> "Making sure CF care is equal for all." – **Nurse, adult care**
>
> "Reducing inequalities in care, and for modulator therapies to be available for all." – **Dietitian, paediatric care**
>
> "Gaining knowledge on best treatment regimes in the new era of CFTR modulators, while not forgetting to find effective treatments for those not eligible and those not receiving treatment worldwide." – **Doctor, paediatric care**

Equitable access to psychological and social support was also highlighted as a priority. This is unsurprising, given respondents reported new and increasing mental health, social, and wellbeing needs among the CF community.

> "Ensuring that all patients have equal access to psychosocial care across the UK." – **Other profession, adult care**
>
> "More psychological support for parents, children and young people." – **Doctor, paediatric care**
>
> "Ensuring the right access to specialist psychosocial professionals in CF for all those with CF and their families." – **Clinical psychologist, adult care**

In line with research priorities identified with the CF community through our James Lind Alliance (JLA) Priority Setting Partnership[10] in 2022, reducing the burden of care was highlighted as a priority by CF professionals.

> "More optimisation and de-prescribing for patients on modulators." **– Pharmacist, paediatric care**
>
> "Looking at ways we can make treatment plans less burdensome for patients and their families." **– Nurse, paediatric care**
>
> "Ensuring there is supportive evidence to allow clinicians to be confident in reducing treatment burden in the modulator era." **– Physiotherapist, paediatric care**

Respondents also shared that patient-centred, holistic care was more important than ever to ensure the diverging needs of people with CF could be met now and in future.

> "Responding to results from research to show how we can personalise care better for individual patients." **– Nurse, paediatric care**
>
> "The one-size fits all approach to CF does not work. The population is heterogeneous with very diverse needs and this needs to be considered when improving care." **– Dietitian, adult care**
>
> "Conversations with patients should be more directed by patients needs and wants, rather than a tick-box of what the clinician needs to cover." **– Dietitian, adult care**

Several CF professionals reflected on specific ways in which the focus of care delivery needed to shift from mainly managing respiratory health to prevention-focused approaches, and supporting patients with co-morbidities, mental health, and wellbeing.

> "Moving to proactive preventative care as opposed to the old model of reactive care." **– Other profession, adult care**
>
> "GI health - we have done so much to improve lungs, GI health remains overlooked but is now causing more admissions." **– Dietitian, adult care**
>
> "To continue to improve CF diabetes (CFD) care through networking with other CF centres to ensure best care is being provided here. To continue to improve self-management of CFD and to always bring the most up to date care to those living with CFD." **– Nurse, adult care**
>
> "Arming patients with the skills they need for jobs - lots missed out on key educational years, and with the strict criteria for benefits now, lots feel they do not have the skills necessary for the workplace." **– Nurse, adult care**

Many respondents felt that patient education and empowerment were also key to delivery of quality CF care in future.

> "Empowering patients to manage their own care with healthcare teams as collaborators. A move away from the medical model." **– Physiotherapist, adult care**
>
> "Provision of appropriate evidence-based education to optimise health and wellbeing in a more self-directed manner." **– Dietitian, adult care**
>
> "Empowerment for patients, non-problem focused narratives rooted in self-care to optimise opportunity with health and general wellbeing." **– Clinical psychologist, paediatric care**

10 Cystic Fibrosis Trust and James Lind Alliance, Your Research Priorities (2022)

Development and ways of working

Development and upskilling of healthcare professionals who care for people with CF was seen as a priority by many respondents. This included training for CF MDT members, as well as ward staff and non-CF disciplines.

> "Upskilling the MDT to help manage a wider variety of CF-related issues." **– Other profession, adult care**
>
> "Ensuring CF team's training is protected better." **– Doctor, paediatric care**
>
> "Staff training for the evolving 'new' patients, including succession planning." **– Physiotherapist, adult care**

Continued and enhanced multidisciplinary working was also highlighted as a priority by CF professionals. Many respondents stressed the ongoing need for the different roles and professions in CF MDTs and noted that succession planning was critical to maintaining fully staffed teams and care quality.

> "It is important to keep a specialist MDT team with knowledge and expertise in CF. There are unknown challenges with modulators and those that are not eligible still require the knowledge and skills of an experienced MDT." **– Dietitian, paediatric care**
>
> "To ensure that succession planning of CF MDT staff with experience and knowledge is acknowledged, and investment and priority given to education so this extremely valuable aspect of CF MDT care is not lost." **– Nurse, adult care**
>
> "Continuing effective MDT working to provide person-centred care in a timely manner - maintaining preventative work as well as working with community systems to meet identified needs." **– Clinical psychologist, paediatric care**

Enhanced collaboration with other disciplines, both in the community as well as secondary and tertiary care was also seen as a priority by CF professionals in our survey.

> "Improved links to other specialities for patients developing comorbidities and improved holistic care." **– Physiotherapist, adult care**
>
> "Interdisciplinary team working: Working alongside GPs to ensure patients attend regular health checks that are not CF related. Linking with obstetrics teams as required. Linking with MSK, pelvic health teams." **– Physiotherapist, adult care**
>
> "I think there is a real risk that services will deteriorate if commissioners place different values on the care that our patients should receive. I think this will require our team to build on relationships with primary care, improve communications and be prepared to fight for the services that we provide." **– Pharmacist, paediatric care**

CF professionals' top priorities for improving CF care focused on:

- Equitable access to treatment and support, while reducing the overall burden of care for all people living with CF.
- Delivery of holistic, person-centred care that adapts around patient needs and empowers people with CF and their families.
- Continued education and development, as well as enhanced collaboration within and beyond CF teams, to ensure care can meet the changing and diversifying needs of the CF population.

3. Ideas for the future

Survey question: What would be your top three ideas for the future of CF care?

Survey respondents shared more than 350 ideas for the future of care. These were frequently aligned with top priorities, but tended to be more focused and actionable.

Care delivery and patient engagement

Equitable access and adherence to effective treatments were seen as critical. Ideas linked to this topic included extending modulator access, developing new therapies, reviewing and streamlining treatment regimens, and reducing burden where possible.

> "Try all patients on modulators and stop if no benefit, rather than have a two-tiered system of those who can and those who can't." – **Nurse, adult care**
>
> "Working to maintain the benefits gained through new modulators, and having access to research for highly effective treatments for people who are not eligible for current modulators." – **Nurse, adult care**
>
> "Understanding which maintenance treatments are required or not required in the post modulator era." – **Doctor, adult care**
>
> "Streamlining patient therapies - thinking once per day modulators." – **Nurse, adult care**

Opportunities to reduce the burden of care, in addition to reducing treatment burden, were highlighted by several respondents, who often emphasised their ambition to enable people with CF to live normal lives. Ideas under this theme included patient-initiated contact, increased use of community care, and reducing the frequency of assessments and appointments.

> "More community-based care. Rationalising appointments and investigations." – **Nurse, adult care**
>
> "Stepping away from the more intense models of care we have worked in previously and allowing people with CF to lead a relatively normal life with light touches from their CF team." – **Other profession, adult care**
>
> "Could frequency of outpatient appointments be stretched out with the introduction of modulators? Perhaps 3 monthly instead of 2 monthly." – **Nurse, paediatric care**
>
> "A two-tier service according to whether patients are on treatment with effective CFTR modulators. The use of algorithms to provide a more bespoke service according to individual need." – **Doctor, paediatric care**

Along with a changing focus of care, CF professionals also shared ideas about approaches to care delivery and suggested leveraging technology to reduce burden of care.

> "Movement towards virtual wards/clinics." – **Physiotherapist, adult care**
>
> "Access to technology to enable self-care." – **Nurse, paediatric and adult care**
>
> "Improved adherence tech - e.g. medication adherence, inhaler monitoring." – **Physiotherapist, adult care**
>
> "I think care needs to become more hybrid so more community working with the ability for some of the MDT to have a virtual consultation at the same time as another member may be with the patient F2F collecting data/samples." – **Undisclosed profession/setting**

In line with ambitions to reduce burden and empower people with CF to self-manage, respondents shared ideas about education and resources to enable this. These touched on a number of different topics, from information about treatments and health risks to healthy lifestyle advice.

> "Increase education around modulators - many people don't actually understand what they do/how they work - accessible resources about this. [And] education about diet." **– Clinical psychologist, paediatric care**
>
> "Health education around hypertension, cardiovascular diseases etc."
> **– Pharmacist, adult care**
>
> "Providing more education on a healthy lifestyle for the future."
> **– Dietitian, paediatric care**

While reduced treatments and contact were deemed appropriate for those doing well on modulators, several CF professionals felt more support should be available for those who needed it. This included enhanced offers to support with mental health, social determinants of health, and wellbeing. Ideas under this theme emphasised the importance of psychosocial care and highlighted unmet needs within the CF community.

> "More focus on the social rather than medical determinants of CF care and support. Addressing the multiple presentation of 'poverty' in CF care – financial, housing, access to NHS care and medications, social connections – to drive down the current rate of loneliness and isolation some CF patients and carers face."
> **– Other profession, adult care**
>
> "Provision of a platform with tools and training modules that people with CF can access to enable them to join the job market and look forward to a more normal future." **– Nurse, adult care**
>
> "Managing CF in the context of neurodiversity (e.g. sensory sensitivities, experience of admissions and appointments, transition etc.)"
> **– Clinical psychologist, paediatric care**

Another area where respondents felt more support should be offered in future was transition from children's to adult services.

> "Building on transition particularly for those patients moving to new centres where adult CF care is not facilitated at their local hospitals." **– Nurse, paediatric care**
>
> "Improved transitional support - this is something that I am really keen on doing to make the move from paediatric to adult care as smooth as possible."
> **– Other profession, paediatric and adult care**

Finally, several respondents emphasised that people with CF and families should be consulted and involved in developing the new model of care and in service redesign.

> "Engage with the community to determine the most appropriate model of care for the post-modulator world." **– Doctors, paediatric care**
>
> "Co-developing with patients/families the new model of care."
> **– Other profession, adult care**

Development and ways of working

In line with priorities set out in Section 3.2, continued education for CF MDT staff as well as others who care for people with CF was felt to be important. Respondents shared ideas for specific topics where staff may benefit from more or new training.

> "Developing staff to be able to deal with newly discovered complications / complications that are expected to arise." – **Physiotherapist, paediatric care**
>
> "More education for CF teams about the social determinants of health/CF and what services might be able to do to tackle these. Some kind of website to connect UK CF professionals (and the various professional staff groups), ideally, we could also post information for people with CF and families." – **Clinical psychologist, adult care**
>
> "More training on treating the ageing population, such as menopause and HRT management. More focus on non-respiratory related issues, such as gastro, diabetes, pain." – **Other profession, adult care**
>
> "More support and education for primary and secondary care on how to care for and manage these patients." – **Undisclosed profession/setting**

Some respondents also suggested a move away from consultant-led models with more clinics and interventions delivered by other roles in the CF MDT.

> "MDT-led clinics for select patients." – **Pharmacist, adult care**
>
> "Increasing nurse led clinics/consultations." – **Nurse, paediatric care**
>
> "Psychologist led MDTs." – **Clinical psychologist, adult care**

Aligned with priorities around more collaboration beyond the CF MDT, several respondents recommended multi-agency working and highlighted other health professionals and community services that CF teams could work more closely with.

> "Focus on building working relationships with primary care." – **Clinical psychologist, Adut care**
>
> "Better links to other specialities (e.g. obstetrics, renal)." – **Physiotherapist, adult care**
>
> "Stronger links with external activity providers." – **Physiotherapist, paediatric care**

Research

With the rapidly changing CF care landscape, health professionals also shared several ideas for research needed to generate evidence around emerging issues and uncertainties, including long-term effects of modulators and co-morbidities.

> "Researching psychological sequalae of life changing modulators." – **Clinical psychologist, adult care**
>
> "Further research to ascertain need for long courses of antibiotics, eradication regimes for CF bugs, and cross- infection rules for those on modulators." – **Doctor, paediatric care**
>
> "Look into the gut microbiome and its possible role in inflammation. Investigate role of CFTR mutation on other systems not lung/gut e.g. brain development, motor skills, muscle strength." – **Physiotherapist, paediatric care**
>
> "Increase research/resources on frailty, and how this occurs at younger age than general population." – **Physiotherapist, adult care**

Recommendations and next steps

Key insights

Our workforce survey clearly shows that many CF professionals are experiencing a shift, rather than an overall reduction in workload. While inpatient and acute workload has reduced in line with hospital statistics and UK CF Registry data on admissions and IV days, outpatient, virtual, and community work has increased for many working in CF. Care is also shifting from respiratory-focused care to more holistic, person-centred care focused on quality of life and prevention of exacerbations.

Paediatric and adult CF care are evolving differently. There are commonalities, such as significant improvements in population health and reductions in inpatient workload, as well as many shared challenges, including increasing psychosocial needs, medicine supply issues, and staffing shortages. However, there are also several important differences in the experiences of professionals working in each setting.

In paediatric care, children with CF who can benefit from modulators are much healthier, which many professionals found rewarding and encouraging. However, some shared concerns about adherence and challenges around keeping children and young people engaged with important treatments and appointments when they felt healthy.

The focus in paediatric settings is shifting to preventative care, looking to support families to self-manage the condition and enable children to have as normal a childhood as possible, with careful monitoring to prevent deterioration. At the same time, there remains a need to care for acutely unwell children, such as babies born with meconium ileus (bowel obstruction), as well as those who cannot benefit from current modulator therapies. Respondents in our survey shared concerns about loss of skills and expertise, as CF professionals encounter fewer severe cases, and felt continued education and development were key to prevent deskilling. Some also suggested it may be appropriate for staff working in paediatric CF care to start working more across other disciplines due to the changing focus and workload in CF and to maintain skills.

The adult population with CF has also experienced significant improvements in health, but many are living with pre-existing lung damage, CF diabetes and other co-morbidities, hence continue to need support from CF teams. In addition, a minority cannot benefit from modulators and continue to require more traditional care. The adult CF population is also growing, while resources for CF care have remained the same or, in some cases, reportedly reduced.

Additionally, adults with CF now live longer, which means more people need support with fertility and pregnancy, as well as conditions of ageing, such as menopause, cardiovascular issues, and cancer. Our survey reveals that more CF professionals in adult care perceive increases in workload across many areas of work compared to their colleagues in paediatric settings.

The focus in adult settings is, therefore, shifting to non-respiratory symptoms and conditions, including those associated with ageing. Enhanced collaboration with other disciplines, while important in both settings, was raised more frequently by respondents from adult care, who made particular reference to obstetrics, gastroenterology, diabetes, and geriatric teams, as well as primary care.

Recommendations

Based on the experiences and ideas shared by more than 150 CF professionals in our survey, we can make several recommendations. Some apply to care delivery, while others relate to team development and ways of working.

Access to effective treatments for everyone with CF was a key priority shared by those working in CF. Respondents highlighted a need for more research to find therapies for those who cannot currently benefit from modulators, but also shared that medication supply issues, particularly with Creon,[11] were a major challenge and needed to be resolved.

CF professionals reported improvements in health for many people with CF, for whom the focus of care is now shifting to more holistic, preventative approaches, while others still require acute interventions and care. This was seen as an opportunity to empower those patients who have improved to self-manage more, reducing the burden of care and disruption to people's lives. In line with this, survey respondents also suggested reducing the burden of care by using new technologies, virtual and remote options, as well as exploring where treatments could be reduced for those doing well on modulators.

Our survey respondents reported that care is moving from inpatient to outpatient and community settings, with many patients seeing fewer exacerbations and requiring less acute care. However, this means fewer opportunities for CF professionals to maintain skills and for junior professionals to develop skills in acute and complex CF care. Therefore, efforts should be made to support staff to maintain and develop skills to care for all people with CF, including those who continue to require more traditional CF care, and those experiencing new and emerging issues and co-morbidities. Guidelines, standards and protocols should be reviewed and updated to reflect the changing face of CF care to guide professionals in their work. Additionally, staff may need training and support to upskill and enable them to care for a diversifying CF population.

The survey findings also highlight a need for role descriptions and job plans to be reviewed so they reflect the changes in workload experienced by many professionals in CF. It is likely that work has not changed in the same way for everyone, as this will depend on the model of care in use, roles in the team, and the needs of the local population. Therefore, individual staff should be involved in these reviews to share their perspective on how work has changed for them. Updated guidance on roles and responsibilities in multidisciplinary CF care is included in section 3 of the Standards for the clinical care of children and adults with CF to support such discussions.[12]

One of the key challenges highlighted by survey respondents focused on staffing and resourcing for CF teams. In particular, many respondents felt more psychosocial roles were needed to support with the increasing mental health, social, and wellbeing needs of the CF community. Additionally, many shared concerns around succession planning across the different professions in CF. It is crucial that CF services are equipped with the resources they need to provide fully staffed CF MDTs now and in future, which should include specialist emotional and social support.

Furthermore, CF professionals in adult care reported an increasing need for support with co-morbidities, fertility, pregnancy, menopause, and conditions of ageing. Closer collaboration between CF teams and other providers, including primary care and specialist teams such as gastroenterology, gynaecology, diabetes, and geriatrics, will likely become increasingly important.

CF workload will continue to evolve and adapt to changes in population needs and care delivery. It is therefore important to continue to monitor how experiences of those working in CF change over time to identify early any trends or new challenges that could impact quality of care.

11 Cystic Fibrosis Trust, Our work on Creon shortages (2024)

12 Cystic Fibrosis Trust, Standards for the clinical care of children and adults with cystic fibrosis in the UK, Third edition (2024)

Recommendations:

For care delivery

- Ensure there is equitable access to care and treatments for all people with CF and address medication supply issues.
- Where appropriate, shift the focus of care to more holistic, preventative approaches to enable people with CF to live a fulfilled life, but retain capacity to deliver high-quality acute care for those who still need it.
- Empower patients:
  - Provide the support and resources needed to self-manage where feasible.
  - Try to accommodate preferences, e.g. for appointment format and frequency.
  - Involve service users in designing new models of care and services for CF.
- Reduce burden of care by leveraging technology and implementing more flexible, person-centred approaches to care.

For team development and ways of working

- Support CF professionals to maintain skills, and junior staff to develop skills, to care for all people with CF, including those requiring more traditional CF care.
- Support CF professionals to access training and resources in relevant emerging areas.
- Review guidelines, standards and protocols to ensure they provide those working in CF with the most up-to-date guidance on care delivery.
- Regularly review role descriptions and job plans for those working in CF to ensure they reflect changes in work and activities delivered.
- Enhance psychological and social support available to meet increasing need.
- Ensure adult CF services are resourced to respond to a population that is increasing in size and complexity.
- Encourage robust succession planning in CF teams and support training for the next generation.
- Enhance collaboration between CF teams and other providers.

Our next steps

As an intermediary between the CF community, researchers, medical professionals, NHS, and governments, Cystic Fibrosis Trust remain committed to fostering and supporting continued progress in the care of people with CF until everyone can live without the limits imposed by CF.[13]

We will continue to advocate for equitable access to CF care and treatments, and to fund vital research into new therapies. Our research priorities, developed through the James Lind Alliance (JLA) Priority Setting Partnership, align with several of the priorities shared by CF professionals in the survey, including projects looking at opportunities to reduce the burden of care, such as CF STORM.[14]

Cystic Fibrosis Trust has already worked with CF professionals to update the Standards for the clinical care of children and adults with cystic fibrosis in the UK, which were published in August 2024.[15] In addition, we have also updated the guidelines for clinical psychology services in CF,[16] as well as the standards for nursing management of CF.[17] We continue to collaborate with CF professionals to update existing guidance and resources, as well as develop new guidelines or standards where required. To support the CF community, we have also updated many of our information resources and are developing new resources about emerging issues.

We are now exploring if we can create more opportunities for CF professionals to access informal training, networking opportunities and peer support, and will work with our Clinical Advisory Group and CF professional interest groups to deliver these.

We are providing anonymised feedback from the survey to CF professional interest groups to share key insights at profession-level and enable these groups to reflect on the challenges and needs shared by their peers. We will also continue to monitor how CF care is evolving for those working in the UK.

Future surveys

The CF workforce survey will re-run in 2028 and an updated report on workload and experiences of CF professionals will be published in the summer of 2028.

In the meantime, we welcome any feedback on this publication, as we are keen to continuously improve how we report on our findings, so that these publications are as useful as possible for the clinical CF communiy and beyond. To share your suggestions, simply email us at **QI@cysticfibrosis.org.uk**

13 Cystic Fibrosis Trust, The Future of CF Care, CF Life Magazine Issue 18 (2025) p28-32
14 Cystic Fibrosis Trust, The CF STORM Trial: A trial investigating the effects of stopping nebulised therapies for people on Kaftrio (2022)
15 Cystic Fibrosis Trust, Standards for the clinical care of children and adults with cystic fibrosis in the UK, Third edition (2024)
16 Cystic Fibrosis Trust, Guidelines for UK clinical psychology services in cystic fibrosis (2024)
17 Cystic Fibrosis Trust, Standards for the nursing management of cystic fibrosis 2nd edition (2025)

Glossary

Word/phrase	Meaning
CAG	Clinical Advisory Group for Cystic Fibrosis Trust
Centre	Hospital providing expert care and specialised disease management for people living with cystic fibrosis.
CF	Cystic fibrosis
Clinic	A smaller local hospital where CF care may be delivered, usually in collaboration with a larger CF centre in a network.
Community support	Care that is delivered locally or at home.
GI	Gastrointestinal
IVs	Intravenous antibiotic therapy a course of antibiotics given through the vein to treat an infection, which can be administered at hospital or at home.
JLA	James Lind Alliance
MDT	Multidisciplinary Team: your CF team is made up of each discipline, such as nurse, physio, social worker, and dietitian.
MSK	Musculoskeletal
NHS	National Health Service
NICE	National Institute of Clinical Excellence provides guidance, advice and information services for health professionals.
PERT	Pancreatic Enzyme Replacement Therapy a treatment used in CF, for example, Creon.
PREMs	Patient-reported experience measures
QI	Quality Improvement a framework we use to systematically improve the ways care is delivered to patients.
QI WG	Quality Improvement Working Group a group of health professionals, people with CF and parents working to improve the way care is delivered to those living with cystic fibrosis.
Respondents	Healthcare professionals who work in CF, including all members of the MDT (nurses, doctors, physiotherapists, dietitians, clinical psychologists, social workers, pharmacists and more).

Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

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