

UK Cystic Fibrosis Service Resourcing 2022 to 2024

Based on findings from the annual Cystic Fibrosis Trust staffing tool

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UK Cystic Fibrosis Service Resourcing

2022 to 2024

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Summary

Participation

In October 2024, 51 of 58 CF centres across the UK completed the staffing tool. This included 26 paediatric and 25 adult CF centres. Staffing information, which is submitted by centre staff themselves, provides us with a snapshot of CF service staffing levels each year. This report summarises the staffing tool findings from three data collections (October 2022, 2023 and 2024), focused mainly on data from October 2024.

Key insights

- Overall staff time in many participating CF centres was lower than what is recommended in the Standards of Care. While some variation is warranted based on models of care in use, several CF centres reported gaps in certain professions and staffing challenges:
 - Two paediatric and one adult centre did not have CF psychology input.
 - 16 paediatric and 14 adult centres lacked a CF social worker.
 - Five paediatric and two adult centres did not include a CF pharmacist.
 - A larger proportion of paediatric CF services appear to lack roles for CF social workers or pharmacists in their team compared to adult services
 - Some CF teams include additional roles that are not funded from CF budgets but deliver care for people with CF. Access to such roles varies and does not address the gaps in social work and pharmacy staffing. However, diabetes and research staff are frequently funded this way.
 - Overall staff time available to the CF population across participating centres fluctuates, and it will be vital to keep monitoring this in future, particularly with the adult CF population expected to grow.

- Services for adults have more vacant staff time year-on-year compared to paediatric services.
- Similar to the NHS overall, CF services are facing issues with vacancies and recruitment. In October 2024, the vacancy rate in participating CF centres was higher than the NHS vacancy rate overall at 12.2% versus 7.2%.
- Over 40% of uncovered vacancies in participating CF services remained unfilled for six months or longer.
- More than half of participating CF services say they are not satisfied with their staffing levels year-on-year.
- CF teams face several staffing challenges, with many citing inadequate provision as a key issue, alongside staff shortages, recruitment challenges and high workloads.
- CF services across the UK continue to adapt and innovate to mitigate staffing challenges and meet the needs of their patients. Key innovations include developing existing staff and adapting how care is delivered, though despite these innovations, staffing often remains a challenge.

Introduction

Specialist multidisciplinary teams (MDTs) are central to the care of people living with cystic fibrosis (CF) across the UK. These MDTs are made up of CF specialists from different professions, including doctors, nurses, dietitians, physiotherapists and other staff, so that they can holistically manage the physical as well as mental health and wellbeing of people with CF under their care. Cystic Fibrosis Trust's Standards of Clinical Care of children and adults with cystic fibrosis¹ and the NHS RightCare CF Toolkit² provide consensus guidance on the composition of CF MDTs and care delivery.

The multidisciplinary, specialist approach to CF care has resulted in huge improvements in care and, most importantly, the health outcomes and experiences of people with CF and their families. In the decade from 2013 to 2023, the proportion of people with CF aged 16 or over steadily increased, with the median age of the CF population in 2023 at 22 years³. Furthermore, in 2023, median predicted survival for babies born with CF today increased to 64.1 years, climbing over 60 years of age for the very first time.

To continue this trend of ongoing improvement, it is essential to ensure that CF centres have sufficient staff and resource to meet the evolving and diversifying needs of the population and provide safe, high-quality care. This care must be accessible in a timely manner to those who need it. CF increasingly needs to be treated as a multisystem condition, as lung function improvements from modulator therapies are shifting the focus of many patients' concerns onto other aspects of their physical and mental health and wellbeing. Additionally, cost of living pressures could result in increased demand for financial and benefits advice, as well as mental health and crisis support. There also remains a sizeable minority of people with CF who cannot benefit from modulator therapies and may require more acute CF care to be available. High-quality CF care, therefore, requires appropriate resourcing for all professions in the MDT, access to suitably qualified staff, and effective recruitment and retention of such staff (low vacancy rates), all of which are key priorities for the NHS generally, as well as the UK government^{4,5,6}.

Cystic Fibrosis Trust wants everyone with CF to be able to access the expertise and support they need to live a fulfilled life. We monitor this in a number of ways, including collecting and publishing information on patient outcomes (via the UK CF Registry), staffing levels, and patient experiences, feeding this information back to clinical teams to stimulate Quality Improvement (QI), and sharing our findings more widely to increase reach and impact.

¹ Cystic Fibrosis Trust, Standards for the Clinical Care of Children and Adults with cystic fibrosis in the UK. 3rd edition, August 2024: cysticfibrosis.org.uk/the-work-we-do/resources-for-cf-professionals/consensus-documents

² NHS England, RightCare cystic fibrosis toolkit; 2024: england.nhs.uk/long-read/rightcare-cystic-fibrosis-toolkit/

³ UK CF Registry Annual Report 2023, published Oct2024: cysticfibrosis.org.uk/registryreports

⁴ NHS England, NHS Long Term Workforce Plan, June 2023: england.nhs.uk/wp-content/uploads/2023/06/nhs-long-term-workforce-plan-v1.2.pdf

⁵ The Health Foundation, A once-in-a-generation opportunity to tackle the NHS's workforce crisis, July 2023: health.org.uk/news-and-comment/blogs/a-once-in-a-generation-opportunity-to-tackle-the-nhs-s-workforce-crisis

⁶ Gov.uk, Government to tackle NHS workforce crisis with refreshed plan, Dec 2024: gov.uk/government/news/government-to-tackle-nhs-workforce-crisis-with-refreshed-plan

Scope of this report

This report presents an overview of staffing information collected from participating CF centres across the UK once annually via the Cystic Fibrosis Trust staffing tool (in October 2022, 2023 and 2024). It is specifically focused on staff time funded from CF budgets and spent caring for people with cystic fibrosis.

This summary report is designed to stimulate discussion about CF service resourcing within participating centres and beyond. We also hope that the insights from this work will be useful to understand how staffing levels in CF services in the UK change over time. This is especially important as modulator therapies are transforming the health and needs of many in the CF population, alongside dramatic changes in digital health offerings^{7,8} and the wider NHS funding landscape, with persistent staffing challenges continuing to impact on services.

Information within this report is drawn from three years of staffing data. The most recent findings from October 2024 are presented, alongside data from preceding years, where relevant, to facilitate comparisons and to enable early identification of any changes that may positively or negatively impact CF care delivery.

Services can use the information in this report alongside their own staffing data to review staffing levels and reflect on how their service compares. However, when exploring staffing levels, it is important to also consider the needs and preferences of the local patient population, access to primary care and other healthcare teams, as well as additional factors that could impact on staff cover needed. In adult care, workforce planning also needs to account for the diversifying needs of a growing and ageing adult population with CF.

Data collection and participation

Each year since 2019, Cystic Fibrosis Trust has invited all specialist CF centres to complete our dedicated 'staffing tool' to share detailed information about professions working in CF, contract types, banding, vacancies, and satisfaction with staffing levels. The tool collects this information directly from CF services via the UK CF Registry system each October; as such, it provides an annual snapshot of staffing levels.

While services are not required to complete the staffing tool, most specialist CF centres have contributed data in the last three years. The number of participating centres and the size of the populations they care for varies year-on-year. Clinics that enter their own UK CF Registry data can individually contribute to the staffing tool, but responses are combined with their network centre in analyses.

This report is based on data collected from 51 of 58 CF centres in the UK (88%) in October 2024 and also draws on staffing data from previous years, which were based on slightly different numbers and combinations of centres (Table 1). Over 70% of CF centres in the UK contribute to the staffing tool each year, but participation is voluntary. While there is some overlap in the sample year-on-year (n=27), the number of participating services varied, and some services contributed data in just one or two years.

⁷ Prickett, Michelle H et al. (2022). Telehealth and CFTR modulators: Accelerating innovative models of cystic fibrosis care. Journal of Cystic Fibrosis Jul 22;S1569-1993(22)00600-2

⁸ Gov.uk, Cystic fibrosis drugs Kaftrio and Kalydeco licensed for patients aged two to five years old, Nov 2023: gov.uk/government/news/cystic-fibrosis-drugs-kaftrio-and-kalydeco-licensed-for-patients-aged-two-to-five-years-old

Table 1: Participation in staffing tool by centre type, year and total population*

	2022	2023	2024
Paediatric centres &	78.1% (25 of 32)	71.9% (23 of 32)	86.7% (26 of 30)
population	Full care: 2,346	Full care: 2,155	Full care: 2,383
	Shared care: 1,437	Shared care: 1,051	Shared care: 1,537
Adult centres & population	64.3% (18 of 28)	82.1% (23 of 28)	89.3% (25 of 28)
	Full care: 3,555	Full care: 5,828	Full care: 6,423
	Shared care: 239	Shared care: 151	Shared care: 143
Total centres	71.7% (43 of 60)	76.7% (46 of 60)	87.9% (51 of 58**)
	Full care: 6,970	Full care: 7,983	Full care: 8,806
	Shared care: 1,676	Shared care: 1,202	Shared care: 1,680

^{*}Population figures show full care as well as shared care (SC) numbers; shared care patients were proportionally attributed in staff time calculations (Section 2) based on information provided by centres as to the proportion of care SC patients receive from CF staff declared in the staffing tool.

Considerations

The Standards of Clinical Care of children and adults with cystic fibrosis⁹ recommend that the minimum size for designation as a Specialist CF Centre should be 100 children or 200 adults with CF, including any shared care or outreach clinic patients. Staff time in this publication is therefore usually described as Whole Time Equivalents (WTEs) per 100 paediatric or 200 adult patients to align our reporting with the current Standards. This also allows easier comparison of staffing levels between CF centres of differing sizes but does not adjust for any other factors. However, use of WTE per 200 adults may result in seemingly high numbers for adult centres that are currently smaller than the recommended size. This should be considered when reviewing WTE median tables.

Data presented in this publication are based purely on staffing tool data submitted to Cystic Fibrosis Trust by participating CF services and reflect actual staffing levels across these services. Average WTE levels across our sample do not indicate a recommended or desired level of staffing and do not imply that services at or above the average WTE level are adequately staffed.

Findings within this report can be reviewed in the context of recommendations within the new Standards of Care⁹. However, it should be considered that some differences between our data and staffing level recommendations in tables 1 and 2 of the Standards may be warranted. The new Standards acknowledge the need for CF teams to continuously adapt and innovate to ensure services best meet their local populations' needs. Therefore, staffing levels observed in the staffing tool may differ from recommended levels for core MDT roles in the Standards due to:

- different models of care in place, for example, nurse-led services may have more nursing time and less consultant time in their CF MDTs compared to the model outlined in table 1 and 2 of the Standards;
- services introducing new and emerging roles to complement other professions in the CF MDT, for example some services now include youth workers, occupational therapists and CF practitioners;
- other local factors, including shared care arrangements and access to non-CF services within hospitals, as well as community and primary care services.

^{**}In 2024, the number of paediatric CF centres reduced from 32 to 30 due to mergers.

⁹ Cystic Fibrosis Trust, Standards for the Clinical Care of Children and Adults with cystic fibrosis in the UK. 3rd edition, August 2024: cysticfibrosis.org.uk/the-work-we-do/resources-for-cf-professionals/consensus-documents

Limitations

The data collected constitute a snapshot of staffing resources available within CF centres at one point in time (once per year, in October). Staffing levels can fluctuate throughout the year as staff leave or as vacancies are filled, and readers are encouraged to keep this in mind when reviewing the findings, particularly the impact of temporary vacancies on staff availability.

The staffing tool is mainly focused on CF budget-funded roles. This is because funding for CF teams should be at a level sufficient to employ a qualified core MDT of appropriate size to deliver the CF service. CF teams should not need to rely on funding from other budgets to secure core staff for their MDT. However, some CF teams will have access to staff not funded from CF budgets. **Sections 1** and **1.1** include some information about the number of CF centres that have additional staff, and in which professions roles are available.

Collecting accurate CF team staffing information is complex due to the different ways in which CF teams are set up and how roles are funded. While we endeavour to check that the staffing information provided by participating services only focuses on the number of staff and time available for CF care, we rely on centres to report these accurately. There can be great variation in the way that CF teams describe their structures and resources, making it difficult to pool data together and compare configurations across services. For example, attribution of staff time where staff work across several different departments, including but not limited to CF, can be complex, which is why the staffing tool tries to focus solely on CF time. Another issue is the attribution of patients under shared care arrangements because these individuals may receive varying proportions of care from their central specialist CF teams while also receiving some care from local teams.

The primary purpose of the staffing tool is to provide bespoke centre-level data feedback to help CF centres explore their staffing levels in context. To enable this, all participating CF centres are issued with a bespoke summary showing their staffing information against the latest findings from the full staffing tool sample with references to the new Standards. To ensure a centre's staffing tool summary is as useful as possible to the CF team, all participating centres can decide if and how they wish to include network clinic staff and/or shared care patients, depending on their services' setup. As a result, some centres have chosen to focus only on their centre's core CF MDT staff, while others also include clinic staff. Centres may also occasionally change how they complete the staffing tool to ensure their bespoke summary is as useful to their local service as possible, which can impact the full sample findings.

To make our staffing information more accurate, we continuously work to improve how we capture and report information on staffing resources, bed availability and shared care patients. For example, we attribute shared care patients proportionately, where possible, and encourage services to agree on a consistent approach to how network clinics are included in staffing submissions. We have also followed up with services to ensure the information we have is as complete and accurate as it can be and only reflects time dedicated to cystic fibrosis. Data published within this report may, therefore, vary slightly from that in previous publications as it incorporates retrospective amendments submitted by services. The latest publication in the series should be referred to for the most up-to-date information.

We will continue to develop and improve our staffing tool and reports in future, including in light of upcoming new Standards, and we welcome feedback at Ql@cysticfibrosis.org.uk

Section 1 Professions available in CF MDTs

The staffing tool collects details about members of CF multidisciplinary teams (MDTs) to better understand which professions are providing input and are available to support people with CF. CF budgets should be sufficient to employ a core CF team with relevant skills and expertise; the staffing tool focuses on such staff. However, **section 1.1** provides an overview of roles funded via other budgets.

Tables 2 and 3 show the proportion of participating centres each year that said they had at least one active member of staff in each profession. "Active staff" include substantive post holders and cover staff available to input into the CF MDT. This does not mean these centres were adequately staffed in these professions; it merely confirms whether input from the respective profession was available in a centre's CF MDT.

Section 2 provides further detail on available staff time across the different professions.

Table 2: Participating paediatric centres with active staff funded by CF budgets

The below is based on currently available staff only; vacant roles are not included, but covered roles are.

	October 2022		October 2023		October 2024	
	Percent	Centres	Percent	Centres	Percent	Centres
Medical (Doctors)	100%	25 of 25	100%	23 of 23	100%	26 of 26
Nursing	100%	25 of 25	100%	23 of 23	100%	26 of 26
Physiotherapy	100%	25 of 25	100%	23 of 23	96.2%	25 of 26
Dietetics	96.0%	24 of 25	100%	23 of 23	100%	26 of 26
Psychology	80.0%	20 of 25	87.0%	20 of 23	84.6%	22* of 26
Social Work	32.0%	8 of 25	39.1%	9 of 23	34.6%	9* of 26
Pharmacy	88.0%	22 of 25	73.9%	17 of 23	76.9%	20* of 26
Administrative	92.0%	23 of 25	91.3%	21 of 23	96.2%	25 of 26
Research	44.0%	11 of 25	44.0%	8 of 23	34.6%	9* of 26
Other ¹⁰	20.0%	5 of 25	30.4%	7 of 23	34.6%	9 of 26

^{*}Additional centres declared staff funded from other budgets: 2 for psychology, 1 each for social work and pharmacy, 3 for research.

^{10 &}quot;Other" group includes roles such as: welfare advisers, youth workers, CF practitioners, physiologists and exercise therapists

Table 3: Participating adult centres with active staff funded by CF budgets

The below is based on currently available staff only; vacant roles are not included, but covered roles are.

	October 2022		October 2023		October 2024	
	Percent	Centres	Percent	Centres	Percent	Centres
Medical (Doctors)	100%	18 of 18	100%	23 of 23	100%	25 of 25
Nursing	100%	18 of 18	100%	23 of 23	100%	25 of 25
Physiotherapy	100%	18 of 18	100%	23 of 23	100%	25 of 25
Dietetics	100%	18 of 18	100%	23 of 23	100%	25 of 25
Psychology	72.2%	13 of 18	91.3%	21 of 23	92.0%	23* of 25
Social Work	33.3%	6 of 18	52.2%	12 of 23	44.0%	11 of 25
Pharmacy	100.0%	18 of 18	91.3%	21 of 23	88.0%	22* of 25
Diabetes	44.4%	8 of 18	43.5%	10 of 23	48.0%	12* of 25
Administrative	100.0%	18 of 18	100%	23 of 23	100%	25 of 25
Research	50.0%	9 of 18	56.5%	13 of 23	56.0%	14* of 25
Other ¹⁰	61.1%	11 of 18	60.9%	14 of 23	72.0%	18 of 25

^{*}Additional centres declared staff funded from other budgets: 1 for psychology, 1 each for pharmacy and research, 4 for diabetes.

Nearly all participating CF centres confirmed their MDT included doctors, nurses, physiotherapists and dietitians funded from CF budgets. Furthermore, at least one role for psychology funded from CF budgets was available at most CF centres in October 2024. While some centres were impacted by vacancies, most had input from doctors, nurses, physiotherapy, dietetics, and psychology. This is crucial because these are also the professions that people with CF say they need to access the most¹¹.

However, other expertise important for holistic CF care was not always available. Not all children and adults with CF had access to CF specialist social workers and pharmacists, whose availability could change year-on-year and varied between centres. The availability of CF specialist social work and pharmacy in both adult and paediatric care is still variable, with only 20 of 51 participating centres (39.2%) overall confirming access to CF social work staff funded from CF budgets in their CF MDT in October 2024. This is concerning because we know that people with CF face significant financial challenges, exacerbated by the ongoing cost of living crisis, and that CF social workers can help with tailored advice on benefits, housing, finances, education, employment and more¹². The proportion of paediatric centres with specialist CF social worker input was particularly low year-on-year. This does not necessarily mean that patients under the care of centres without a specialist CF social worker cannot access social support. Centres may have welfare advisers or similar roles, or they may refer to social services in the community. However, specialist CF social workers bring expertise and knowledge of the condition that is valued by people with CF and critical to high quality holistic care.

Access to CF specialist pharmacists and social workers was also variable in adult services, though better than in paediatric services. Twelve of 25 adult CF centres (48%) said they funded dedicated diabetes staff.

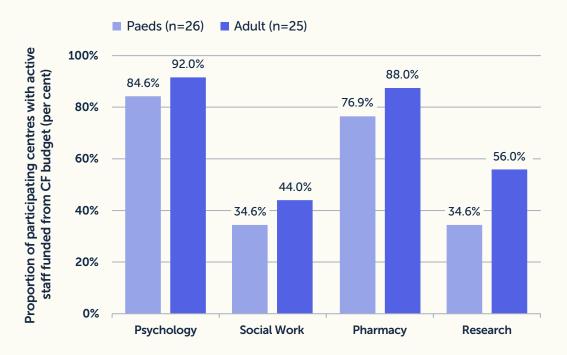
Insight: Not all people with cystic fibrosis consistently have access to a full multidisciplinary team at their CF centre, particularly when it comes to CF specialist social work and pharmacy.

¹¹ Cystic Fibrosis Trust, Patient-Reported Experience Measures; 2024 cysticfibrosis.org.uk/QI

¹² Cystic Fibrosis Trust, Support in crisis: the unseen cost of living with cystic fibrosis; October 2023

When psychologists, social workers, pharmacists, and research staff are available within a team, these roles are often only part time and people with CF may still be unable to access them in a timely manner, even where roles exist. Furthermore, availability of these professions is more easily impacted by vacancies because there is usually only one role in each of these professions in a team, which offers limited resilience when staff leave, retire, or take time off. Some services also reported that they did not have such roles within their CF MDT, while others sourced funding for these roles from budgets other than the CF budget.

Figure 1: CF MDTs with active psychology, social work, pharmacy and research staff funded from CF budgets in October 2024



It is important to understand whether apparent gaps in staffing are due to open vacancies or to a lack of provision for such roles within CF MDTs. Figure 2 provides an overview of the proportions of participating CF centres that had each specialist profession available in the MDT, alongside the proportion that lacked input from these professions. The latter group is split into whether roles were available but vacant or whether there were no roles available in a centre at all. It also shows where centres included such roles but were funding them from other budgets.

This analysis shows nearly all participating adult centres had roles available for CF psychologists, though one (3.8%) temporarily lacked input from this profession due to a vacancy. It also shows that three participating adult CF centres (12%) lacked specialist CF social worker input in the short term, as they had open vacancies, while 11 adult centres (44%) had no roles for CF social workers available. Most adult CF MDTs included a pharmacist, but some were impacted by vacancies.

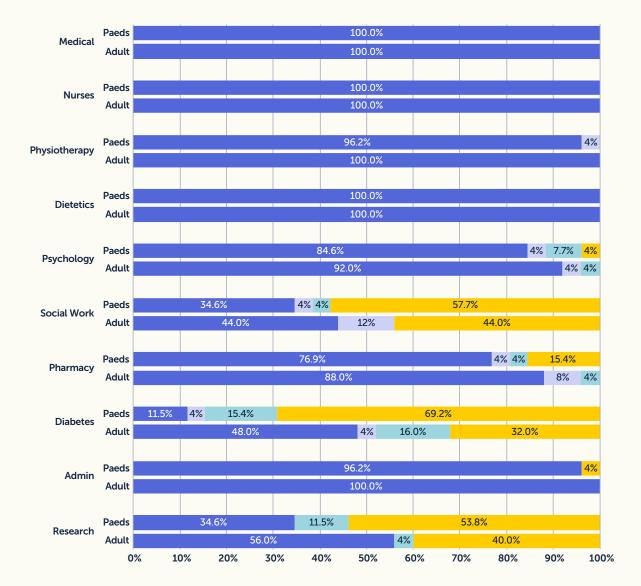
Services for children were less likely to have any CF-funded roles available for specialist social workers in their MDTs, with 15 services (57.7%) not having any roles for social workers available, and one service funding a social worker role from another budget. Four paediatric centres (15.4%) did not have a pharmacist in their CF MDT, and one service sourced this role from another budget.

Figure 2: Availability of core professions in CF services

The below is based on data from participating paediatric (n=26) and adult (n=25) CF centres/networks.

Small numbers have been rounded in the graph below; percentages may add up to slightly more/less than 100% due to rounding.

- Centre had at least one role in this profession (funded from CF budget)
- Centre had at least one role in this profession but this was vacant
- Centre only had staff in this profession funded from other budgets
- Centre had no roles available within this profession



Insight: A larger proportion of paediatric CF services appear to lack roles for CF social workers or pharmacists in their MDT compared to adult services.

1.1 Additional staff

Occasionally, CF teams include additional staff not funded from CF budgets. Where this is the case, the staffing tool explores which additional professions were feeding into CF MDTs, though no further detail about these roles is captured.

Twenty-two of 51 participating centres (43%) had additional staff available in at least one profession: 12 of 26 paediatric centres (46%) and 10 of 25 adult centres (40%). Fourteen of these centres had additional roles in more than one profession, which can be additional to CF-funded roles.

Table 4: Participating centres with at least one non-CF funded role, by profession

The below shows the number of participating centres with staff who were not funded from the centre's CF budget by profession, these roles may be in addition to CF-funded staff in the same profession and centre.

Profession	Paediatric centres with non-CF funded staff	Adult centres with non-CF funded staff
Medical (Doctors)	1 of 26	4 of 25
Nursing	0 of 26	0 of 25
Physiotherapy	1 of 26	0 of 25
Dietetics	0 of 26	1 of 25
Psychology	2 of 26	1 of 25
Social Work	1 of 26	0 of 25
Pharmacy	1 of 26	1 of 25
Diabetes	5 of 26	5 of 25
Administrative	1 of 26	1 of 25
Research	5 of 26	3 of 25
Other	5 of 26	3 of 25

Most commonly, diabetes, research or other staff were funded from budgets other than the CF budget. Social workers and pharmacists were rarely funded this way. While access to additional staff will often be beneficial to CF teams, such staff do not appear to fill the gaps in social work and pharmacy (see Tables 2 and 3). However, they have helped to mitigate some of the gaps in psychology provision identified in previous staffing tool cycles, as three psychology roles within teams that normally would not have a psychologist were funded from outside the CF budget in October 2024.

Insight: Some CF teams include additional roles that are not funded from CF budgets but deliver care for people with CF. Access to such roles varies and does not address the gaps in social work and pharmacy staffing. However, diabetes and research staff are frequently funded this way.

Section 2 Staffing configurations

The make-up of CF teams can differ between paediatric and adult centres, and even between the same types of services. This may be entirely appropriate, depending on service size, patient population, model of care in use, and other factors, such as access to support and services in the community. However, staffing levels may be linked to the ability to meet professional standards and improve clinical outcomes and should, therefore, be monitored. Staffing information provides important insights to help teams explore their local staffing configurations in context.

Table 5a: Median centre-level staff time available per 100 children with CF

Median WTE available per 100 children in sample of 26 participating paediatric centres/networks in October 2024; vacant roles are not included unless they were covered, where a vacant role was covered at a different level to the usual role, the WTE of the cover arrangement was used.

Paediatric Care	WTE per 100 paediatric patients				
	Median*	Range**	Standards of Care ¹³		
		Lowest - Highest			
Overall	8.2	(5.0 – 12.6)	9.25		
Medical (Doctors)	1.0	(0.4 - 3.1)	1.50		
Nursing	2.0	(0.9 - 3.8)	1.75		
Physiotherapy	1.4	(0.0 - 2.7)	2.00		
Dietetics	0.9	(0.5 - 2.1)	1.00		
Psychology	0.4	(0.0 - 1.3)	0.75		
Social Work	0.0	(0.0 - 1.1)	0.75		
Pharmacy	0.4	(0.0 - 1.0)	0.75		
Administrative	0.8	(0.0 - 1.8)	0.75		
Research	0.0	(0.0 - 0.8)	N/A		
Other	0.0	(0.0 - 1.4)	N/A		

^{*} A median of zero means that half or more of participating services reported not having any available staff within the respective profession (they may have had vacant posts in these professions).

^{**} The range shows the lowest and highest staffing level seen among participating centres for each profession; it gives an idea of the differences in level of cover between different centres but does not take fully into account differences in patient population complexity, nor external/other factors.

¹³ Cystic Fibrosis Trust, Standards for the Clinical Care of Children and Adults with cystic fibrosis in the UK. 3rd edition, August 2024: cysticfibrosis.org.uk/the-work-we-do/resources-for-cf-professionals/consensus-documents, Table 1, page 13

Table 5b: Median centre-level staff time available per 200 adults with CF

Median WTE available per 200 adults in sample of 25 participating adult centres/networks in October 2024; vacant roles are not included unless they were covered, where a vacant role was covered at a different level to the usual role, the WTE of the cover arrangement was used.

Adult Care	WTE per 200 adult patients				
	Median*	Range**	Standards of care ¹⁴		
		Lowest - Highest			
Overall	13.8	(6.3 – 23.4)	18.5		
Medical (Doctors)	1.8	(0.7 - 3.5)	3.0		
Nursing	2.8	(1.4 - 7.1)	3.5		
Physiotherapy	3.0	(0.9 - 5.8)	4.0		
Dietetics	1.2	(0.6 - 2.4)	2.0		
Psychology	0.7	(0.0 - 3.7)	1.5		
Social Work	0.0	(0.0 - 1.8)	1.5		
Pharmacy	0.9	(0.0 - 2.1)	1.5		
Diabetes	0.0	(0.0 - 1.0)	N/A		
Administrative	1.7	(0.1 - 3.5)	1.5		
Research	0.3	(0.0 - 2.0)	N/A		
Other	0.6	(0.0 - 2.3)	N/A		

^{*} A median of zero means that half or more of participating services reported not having any available staff within the respective profession (they may have had vacant posts in these professions).

Insight: In October 2024, overall staff time in many participating CF centres was lower than Whole-Time Equivalents (WTE) recommended in the Standards of Care. While some variation is warranted based on models of care in use, several CF centres reported gaps in certain professions and staffing challenges.

The different amounts of staff time available across participating centres (see ranges in Tables 5a and b) show that there appears to be variation in staffing levels between services and across all professions. Some of this variation may be explained by differences in location, population and models of care in use. However, given that many services fed back they were not satisfied with their staffing levels (section 4), it is likely that some variation in time available is due to vacancies and gaps in provision.

Availability of staff can also fluctuate over time. It is, therefore, useful to consider how much staff time was available on average across the population that was being cared for by participating CF centres each year.

^{**} The range shows the lowest and highest staffing level seen among participating centres for each profession; it gives an idea of the differences in level of cover between different centres but does not take fully into account differences in patient population complexity, nor external/other factors.

¹⁴ Cystic Fibrosis Trust, Standards for the Clinical Care of Children and Adults with cystic fibrosis in the UK. 3rd edition, August 2024: cysticfibrosis.org.uk/the-work-we-do/resources-for-cf-professionals/consensus-documents, Table 2, page 13

Figure 3a: Average WTE per 100 children; October 2022, 2023, 2024

Average staff time was calculated based on all posts in participating centres and the total population in our sample (with shared care patients attributed proportionately); where a vacant post was covered at a different level to the usual role, the WTE of the available cover was included in 'covered time', any remaining vacant time is included in 'vacant time' (striped).

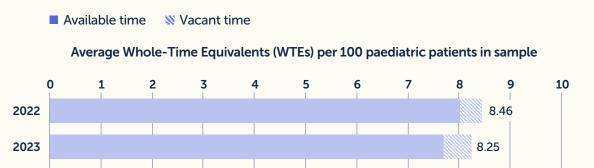


Figure 3b: Average WTE per 200 adults; October 2022, 2023, 2024

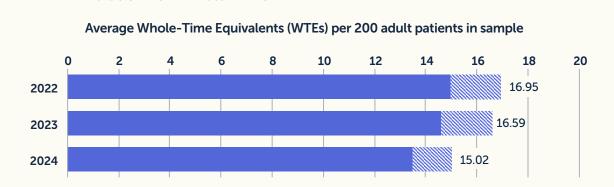
W Vacant time

2024

Available time

Average staff time was calculated based on all posts in participating centres and the total population in our sample (with shared care patients attributed proportionately); where a vacant post was covered at a different level to the usual role, the WTE of the available cover was included in 'covered time', any remaining vacant time is included in 'vacant time' (striped).

8.25



Average staff time for the paediatric population has remained relatively stable in our samples, whereas this decreased year-on-year for the adult population. It is important to keep in mind that fluctuations in average staff time from one year to the next could be driven by differences in the overall number of roles and WTEs that exist in participating services and/or by changes in patient numbers. Vacancies will impact available staff time each year, as a proportion of funded time remains uncovered and is not available to CF patients. Adult centres reported a higher proportion of vacant time year-on-year compared to paediatric centres, though the proportion of time that was vacant in paediatric services also increased in 2024 compared to previous years.

Insight: Overall staff time available to the CF population across participating centres fluctuates, and it will be vital to keep monitoring this in future, particularly with the adult CF population expected to grow.

Insight: Services for adults have more vacant staff time year-on-year compared to paediatric services.

To explore how staff time is distributed across different professions in CF MDTs, Figures 4 and 5 show staff time for each profession in our samples from 2022, 2023 and 2024 (as average WTE per 100 children or 200 adults, respectively).

Figure 4: Average staff time for paediatric population, by profession

Average staff time was calculated based on all posts in a profession (incl. vacant/covered posts) and total population in the sample (with shared care patients attributed proportionately); as per Figure 3a.

Available time Vacant time

Average Whole-Time Equivalents (WTEs) per 100 paediatric patients across participating CF centres

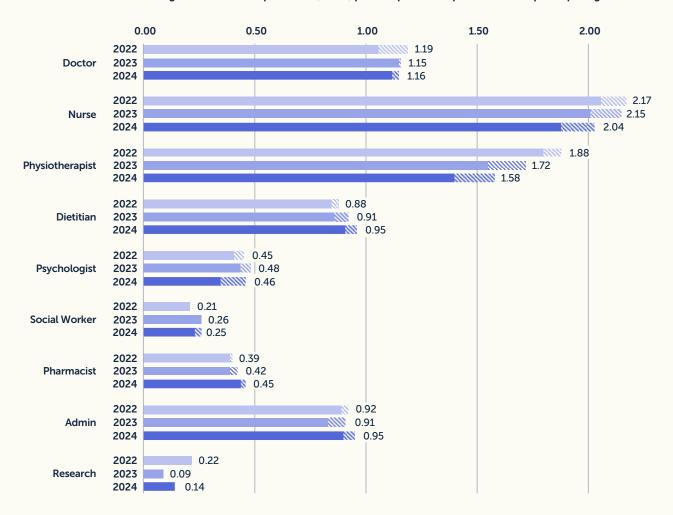
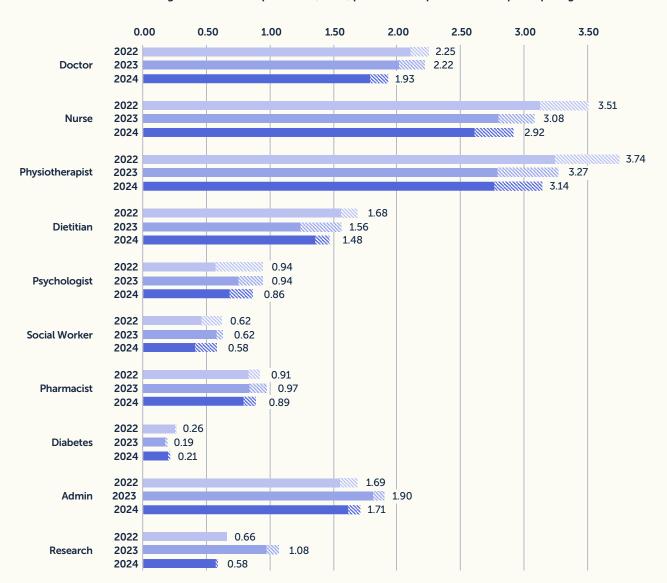


Figure 5: Average staff time for adult population, by profession

Average staff time was calculated based on all posts in a profession (incl. vacant/covered posts) and total population in the sample (with shared care patients attributed proportionately); as per Figure 3a.

Available time Vacant time

Average Whole-Time Equivalents (WTEs) per 200 adult patients across participating CF centres



In paediatric care, average time in our sample fluctuates within a range of approximately 0.03–0.15 WTEs per 100 children for most professions except physiotherapy, where it reduced by 0.3 WTE between 2022 and 2024 (Figure 4). In adult care, average time in our sample fluctuates between 0.05–0.6 WTEs per 200 patients (Figure 5). For nurses, physiotherapists and research staff, fluctuations were more pronounced than for other professions.

In adult and paediatric care, average time in psychology, social work and pharmacy was consistently lower than for the other core professions shown. Diabetes staff were included in the staffing tool for the first time in October 2022, with around 40% of participating adult services declaring diabetes staff funded from CF budgets within their CF MDTs each year since.

When looking at average staff time, it is important to consider context. New modulator treatments for CF have been approved and rolled out to increasing proportions of the population in recent years, improving both life expectancy and quality of life. This means there are now more people living with CF than ever before. When patient numbers rise, an overall reduction in average staff time would be expected over time, particularly in adult CF services, unless there was an uplift to match changes in patient numbers. Fluctuations can also be impacted by differences in our sample of services and or staff availability. Cystic Fibrosis Trust will continue to monitor staffing levels and outcomes via the UK CF Registry and will work closely with the CF community to explore and advocate for the evolving needs of a growing and ageing CF population.

2.1 Staff seniority

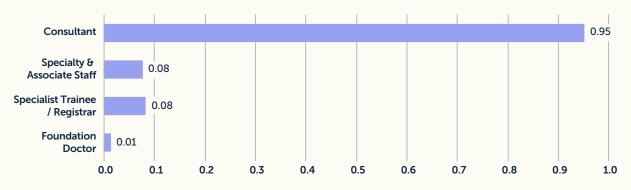
Staffing levels in CF teams also vary by seniority of roles available. In 2019, participating adult centres had a significantly higher proportion of lower-banded posts compared to paediatric centres (24.1% vs. 12.8%). While adult centres also reported larger proportions of roles at Band 5 or below in later years, this difference was not as pronounced. In 2024, 18.4% (136 of 739) of roles in adult care were Band 5 or below, compared to 15.6% (77 of 495) in paediatric care.

Figures 6 to 15 show staff time available to populations under the care of participating services in October 2024 split by seniority level (NHS Agenda for Change banding / medical grading)¹⁵. Open vacancies are not included, but cover arrangements are. Where a vacant post was covered at a different level to the usual role, the WTE of the available cover was included.

To align with the Standards, staff time is shown as WTE per 100 children for paediatric care, and WTE per 200 adults for adult care. Sample populations used in these calculations were based on the total number of people cared for by participating CF centres (see Table 1), with shared care patients attributed proportionally. As such, the sample populations include patients from centres that do not have access to some professions. This will result in low availability figures for such professions when looking at staff time across the full sample population. Therefore, staffing levels shown should not be interpreted as recommended levels but rather provide an indication of the composition of the CF workforce and how CF roles are graded for different professions.

Figure 6a: Medical staff time available per 100 children, by seniority

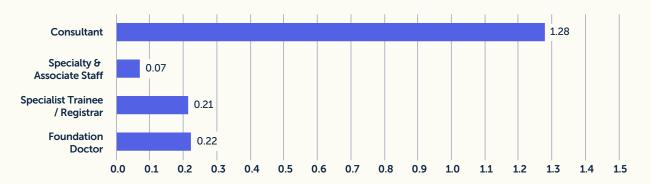
Based on average 1.12 WTE of medical staff time per 100 children declared by participating paediatric services.



Whole-Time Equivalents (WTE) available per 100 children across participating paediatric CF centres

Figure 6b: Medical staff time available per 200 adults, by seniority

Based on average 1.79 WTE of medical staff time per 200 adults declared by participating adult services.

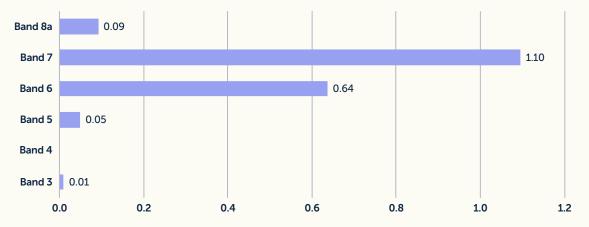


Whole-Time Equivalents (WTE) available per 200 adults across participating adult CF centres

Banding for doctors differs from other NHS banding, with most medical staff in CF centres working at consultant level (Figures 6a and b). Experienced consultants also act as centre directors or leads in many CF centres and clinics. The most junior medical roles (Foundation doctors) were primarily working in adult care.

Figure 7a: Nursing staff time available per 100 children, by seniority

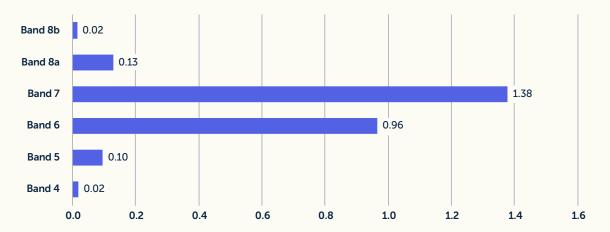
Based on average 1.88 WTE of nursing time per 100 children declared by participating paediatric centres.



Whole-Time Equivalents (WTE) available per 100 children across participating CF centres

Figure 7b: Nursing staff time available per 200 adults, by seniority

Based on average 2.61 WTE of nursing time per 200 adults declared by participating adult centres.

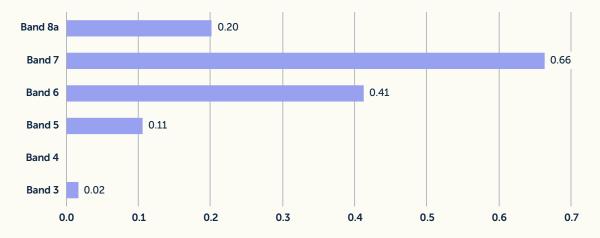


Whole-Time Equivalents (WTE) available per 200 adults across participating CF centres

Nurses provide advocacy and support with diagnosis, treatment and a wide range of other issues. Clinical nurse specialists in CF may also possess additional skills and expertise, for example in prescribing or CF diabetes care. CF nurses are usually employed at Bands 6 and 7, with some higher banded posts that may include managerial responsibilities (Figures 7a and b).

Figure 8a: Physiotherapy staff time available per 100 children, by seniority

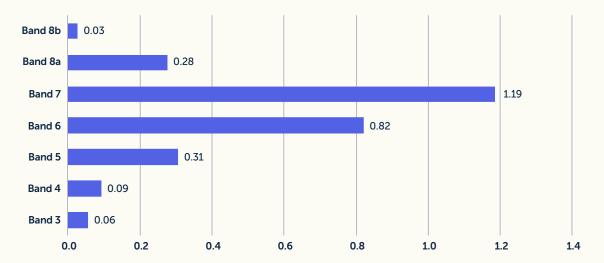
Based on average 1.40 WTE of physio time per 100 children declared by participating paediatric centres.



 $Whole-Time\ Equivalents\ (WTE)\ available\ per\ 100\ children\ across\ participating\ CF\ centres$

Figure 8b: Physiotherapy staff time available per 200 adults, by seniority

Based on average 2.82 WTE of physio time per 200 adults declared by participating adult centres.

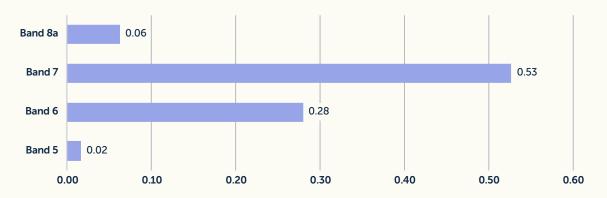


Whole-Time Equivalents (WTE) available per 200 adults across participating CF centres

Physiotherapists are an essential part of the CF team as they support many aspects of care from assessments to treatments in clinic, inpatient, and community settings. Most physiotherapists working in CF are respiratory physiotherapists. However, other backgrounds, such as musculoskeletal physiotherapy, may become increasingly important in future within CF care. Similar to nurses, CF physiotherapists were usually employed at Bands 6 and 7, though some centres also included more senior roles for physiotherapists (Figures 8a and 8b). There were also some lower banded roles (Band 5 and below) available in physiotherapy, which are likely assistants or physiotherapists in training.

Figure 9a: Dietetics staff time available per 100 children, by seniority

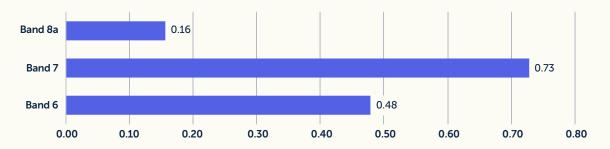
Based on average 0.90 WTE of dietetics time per 100 children declared by participating paediatric centres.



Whole-Time Equivalents (WTE) available per 100 children across participating CF centres

Figure 9b: Dietetics staff time available per 200 adults, by seniority

Based on average 1.36 WTE of dietetics time per 200 adults declared by participating adult centres.

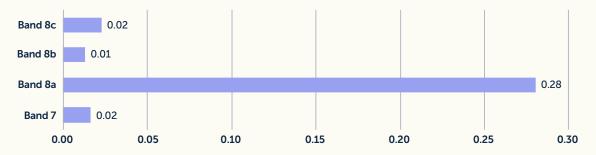


Whole-Time Equivalents (WTE) available per 200 adults across participating CF centres

Dietitians working in CF carry out assessments and provide evidence-based nutritional advice and support, which can include dietary management, supplementation, and pancreatic enzyme therapy. While average time available from dietitians was lower in paediatric and adult CF care than from nurses and physiotherapists, dietitians were also mainly working at Bands 6 and 7 (Figures 9a and 9b).

Figure 10a: Psychology staff time available per 100 children, by seniority

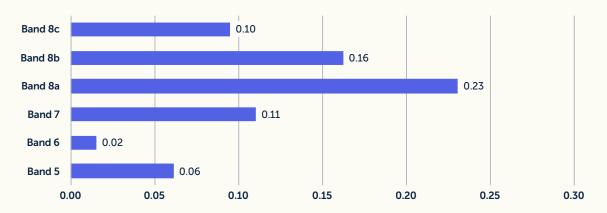
Based on average 0.33 WTE of psychology time per 100 children declared by participating paediatric centres.



Whole-Time Equivalents (WTE) available per 100 children across participating CF centres

Figure 10b: Psychology staff time available per 200 adults, by seniority

Based on average 0.68 WTE of psychology time per 200 adults declared by participating adult centres.

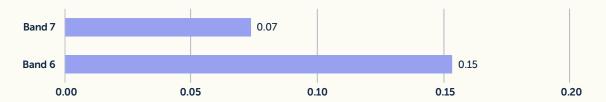


Whole-Time Equivalents (WTE) available per 200 adults across participating CF centres

Clinical psychologists are an essential part of the wider CF team, as they deliver psychological screening, prevention, and intervention activities to support the mental and emotional health of people with CF. While there are gaps in psychology provision in some services, in October 2024, most participating centres reported that they had access to a psychologist within the CF team. Such roles were usually employed at Band 8a in paediatric care, whereas in adult care there was a wider spread of banding for psychology roles (Figures 10a and 10b).

Figure 11a: Social work staff time available per 100 children, by seniority

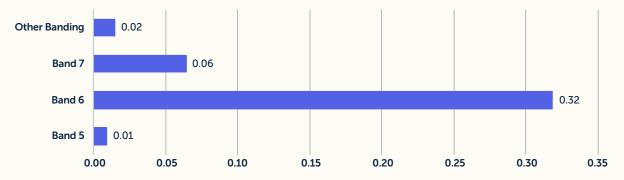
Based on average 0.23 WTE of social work time per 100 children declared by participating paediatric centres.



Whole-Time Equivalents (WTE) available per 100 children across participating CF centres

Figure 11b: Social work staff time available per 200 adults, by seniority

Based on average 0.41 WTE of social work time per 200 adults declared by participating adult centres.



Whole-Time Equivalents (WTE) available per 200 adults across participating CF centres

Social workers, like psychologists, are vital for delivery of holistic CF care. They can offer support with many aspects of life, from finances, housing and employment to social and family functioning, providing expert advice, advocacy and intervention. Social workers in CF teams were most commonly employed at Band 6, with a wider banding spread in adult care compared to paediatrics (Figures 11a and 11b). It is important to note that this is based on time available across the whole population cared for by participating centres. As not all services had social workers in October 2024 (Tables 2 and 3), average time available to the full sample population is lower compared to other professions. This is the case for pharmacy as well.

Figure 12a: Pharmacy staff time available per 100 children, by seniority

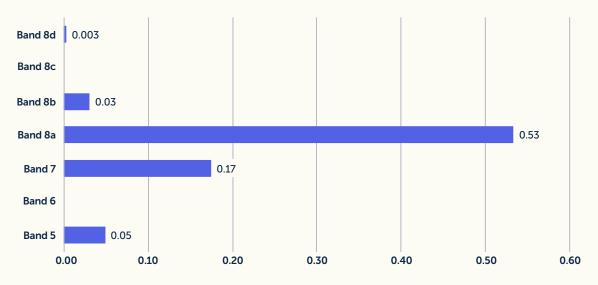
Based on average 0.44 WTE of pharmacy time per 100 children declared by participating paediatric centres.



Whole-Time Equivalents (WTE) available per 100 children across participating CF centres

Figure 12b: Pharmacy staff time available per 200 adults, by seniority

Based on average 0.79 WTE of pharmacy time per 200 adults declared by participating adult centres.



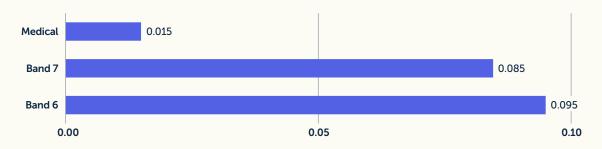
Whole-Time Equivalents (WTE) available per 200 adults across participating CF centres

Pharmacists in CF carry out prescription monitoring and medicine optimisation, liaising with community and other services as needed. They can also advise on adherence and provide education about treatments and medications. Most CF pharmacists are working at Band 8a in paediatric and adult services (Figures 12a and 12b).

In addition to psychosocial and pharmacy staff, the staffing tool also asked about CF diabetes staff within adult CF care.

Figure 13: Diabetes staff time available per 200 adults, by seniority

Based on average 0.19 WTE of diabetes staff time per 200 adults declared by participating adult centres.



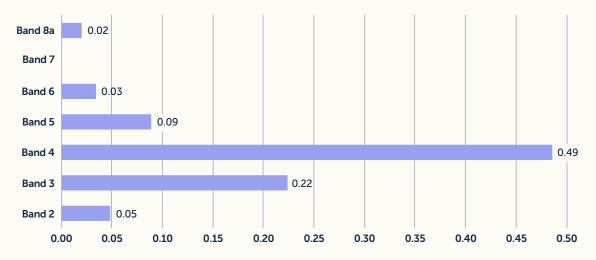
Whole-Time Equivalents (WTE) available per 200 adults across participating CF centres

Figure 13 shows average diabetes staff time available per 200 adults across the adult population in our sample. It is important to keep in mind that only 48% of adult services (n=12) said they had active diabetes staff in their CF team. Other teams may have access to diabetes staff input funded through the specialist diabetes service or may refer to such services.

Roles for administrative staff, such as secretaries and database coordinators, concentrated at Bands 3 and 4 in paediatric and adult CF care.

Figure 14a: Administrative staff time available per 100 children, by seniority

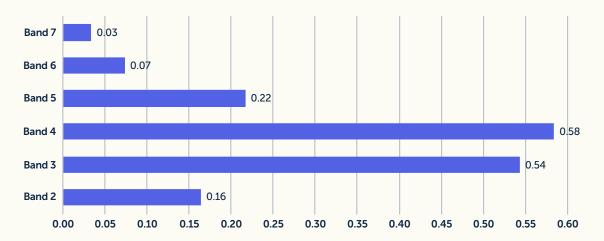
Based on average 0.90 WTE of admin time per 100 children declared by participating paediatric centres.



Whole-Time Equivalents (WTE) available per 100 children across participating CF centres

Figure 14b: Administrative staff time available per 200 adults, by seniority

Based on average 1.62 WTE of admin time per 200 adults declared by participating adult centres.

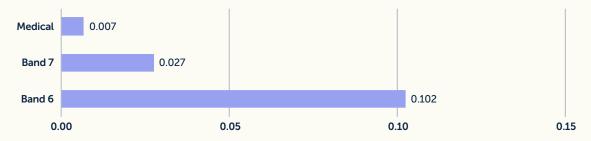


Whole-Time Equivalents (WTE) available per 200 adults across participating CF centres

In addition to professions delivering and coordinating clinical care, people with CF should be enabled to take part in research and clinical trials¹⁶. Dedicated research staff embedded within CF teams can support this by ensuring people with CF and families are informed about and invited to relevant research opportunities.

Figure 15a: Research staff time available per 100 children, by seniority

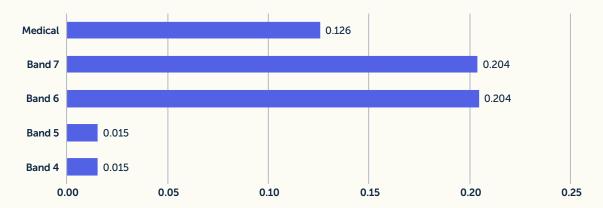
Based on average 0.14 WTE of research time per 100 children declared by participating paediatric centres.



Whole-Time Equivalents (WTE) available per 100 children across participating CF centres

Figure 15b: Research staff time available per 200 adults, by seniority

Based on average 0.57 WTE of research time per 200 adults declared by participating adult centres.



Whole-Time Equivalents (WTE) available per 200 adults across participating CF centres

While dedicated roles for researchers funded from CF budgets are relatively rare, those that exist are usually graded at Bands 6 or 7, with several posts for research staff from medical backgrounds available as well. It is important to note that, even where services did not report access to dedicated CF research staff in the CF team, they may be able to access other research staff within their NHS Trust, which would not be captured by the staffing tool. There were also some research roles in CF teams not funded from CF budgets, which are not shown in Figures 15a and 15b, but an overview is included in **section 1.1**. Overall, the adult population had more dedicated CF research staff time than was available to the paediatric population.

2.2 Contract types

While most roles in CF services are permanent, some staff are on fixed-term contracts (FTCs), which do not guarantee that a role will remain available when the term ends. The proportion of FTCs in October 2024 was 4.9%, while 95.1% of roles declared had permanent contracts. While five per cent of staff on FTCs might not seem much, it means 1 in 20 roles in CF MDTs were only fixed term.

Figure 16: Contract types by profession in October 2024

Based on 1,234 roles in participating paediatric and adult centres, regardless of hours contracted.



Proportion of contracts in each profession that are premanent and fixed-term (per cent)

For all professions except research, over 90% of contracts in place across participating CF centres were permanent, with 0-6.6% of contracts being fixed term, depending on profession. For medical doctors, consultant roles tended to be permanent, whereas others, particularly specialist registrar and trainee roles, were fixed term only. Research staff were the only group that had a substantial proportion of staff on FTCs (36.8%).

Section 3 Vacancies

Even when a centre has active staff in a profession, it may not be fully staffed. This is exemplified by nursing vacancies in the latest dataset, where 31 vacancies were reported across our sample despite all participating centres having active nursing staff. While some vacant time may be covered by temporary staff, it is important to consider the impact of vacancies, particularly roles that remain vacant long term, on CF care delivery.

In October 2024, there were 142 vacancies across 51 participating CF centres, with 19 of 26 paediatric and 21 of 25 adult centres reporting at least one vacancy. To better understand how vacancy rates in CF services compare with the NHS overall, the staffing tool collects information on currently active staff in each service, as well as vacant roles and cover arrangements. Table 6 shows the vacancy rates across participating services from the last three years of the staffing tool. Our approach to calculate the vacancy rate is aligned with NHS England's approach to calculating overall NHS vacancy rate¹⁷ and, therefore, does not indicate how much of the reported substantive gap is covered by temporary staff. The bottom row in Table 6 includes additional information about covered time.

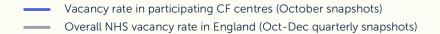
Table 6: WTE workforce and vacancy rates across participating CF centres

	2022	2023	2024
Planned CF Workforce (WTE)	571.27	706.06	741.58
Vacancies (WTE, incl. covered time)	59.78	86.47	90.33
Vacancy Rate* (%)	10.46%	12.25%	12.21%
Covered Arrangements (WTE)	10.13	14.25	20.44

^{*} The vacancy rate is the proportion of WTEs that are not filled by a substantive post holder, out of the total planned / budgeted WTEs for the CF workforce across participating centres; covered vacant time is included as vacant time in this calculation; [Planned Workforce WTE = all active workforce WTE plus vacancies WTE; Vacancy Rate (%) = (Vacancies WTE \div Planned WTE) x 100].

¹⁷ NHS Digital, NHS Vacancy Statistics England [Experimental Statistics: April 2015 – December 2024 – Tables]; March 2025: NHS Vacancy Statistics (and previous NHS Vacancies Survey) - NHS Digital

Figure 17: Vacancy rate over time: 2022, 2023, 2024





In the last quarter of 2024 (October to December), NHS Vacancy Statistics¹⁸ showed a vacancy rate of 7.2% across NHS providers in England, compared to a vacancy rate of 12.2% in participating CF centres in October 2024, though it should be noted that some CF centres were located in devolved nations.

Insight: Similar to the NHS overall, CF services are facing issues with vacancies and recruitment. In October 2024, the vacancy rate in participating CF centres was higher than the NHS vacancy rate overall at 12.2% versus 7.2%.

¹⁸ NHS Digital, NHS Vacancy Statistics England [Experimental Statistics: April 2015 – December 2024 – Tables]; March 2025: NHS Vacancy Statistics (and previous NHS Vacancies Survey) - NHS Digital

Table 7: Vacancies* unfilled for more than six months by profession

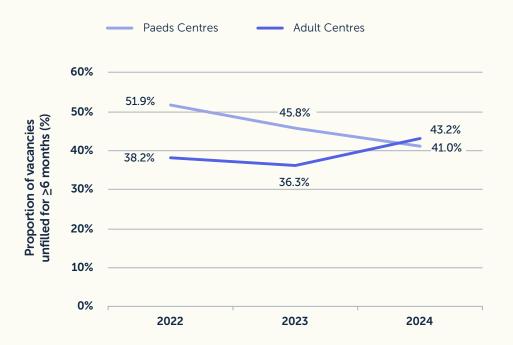
	Paediatric Services (n=26)			Adult Servi	ces (n=25)	
	Proportion vacant ≥ six months	Vacant ≥ six months	Total vacant posts	Proportion vacant ≥ six months	Vacant ≥ six months	Total vacant posts
Medical (Doctors)	33.3%	1	3	87.5%	7	8
Nursing	71.4%	5	7	46.7%	7	15
Physiotherapy	37.5%	3	8	25.0%	3	12
Dietetics	20.0%	1	5	33.3%	3	9
Psychology	50.0%	4	8	55.6%	5	9
Social Work	0%	0	2	50.0%	4	8
Pharmacy	100%	1	1	25.0%	1	4
Diabetes	0%	0	1	50.0%	2	2
Administrative	33.3%	1	3	0%	0	5
Research		0	0	0%	0	1
Other	0%	0	1	0%	0	1
Total proportion of vacancies unfilled for more than 6 months	41.0%	16	39	43.2%	32	74

^{*} Vacancies that are being covered are excluded from the total vacant count in Table 7; further information about cover arrangements is shown in Table 8.

Adult CF services had more vacancies than paediatric services overall. Across participating paediatric and adult CF centres, more than half the vacant posts for nurses (12 of 31, 38.7%) and psychologists (9 of 17, 52.9%) had been unfilled for six months or longer by October 2024.

In previous years, a higher proportion of vacancies in participating children's services had remained unfilled for six months or longer compared to adult services. However, this appears to have changed in the latest data (Figure 18).

Figure 18: Proportion of vacancies unfilled for more than 6 months

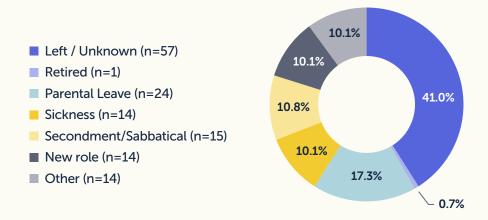


Insight: Over 40% of uncovered vacancies in participating CF services remained unfilled for six months or longer.

3.1 Vacancy reasons

Posts may be vacant for a number of different reasons, such as staff moving on or retiring, or existing staff going on longer-term leave.

Figure 19: Vacancy reasons provided in 2024



In October 2024, fewer than half of all vacancies were due to staff leaving or retiring. More than a third of roles were vacant due to a contracted member of staff on longer-term leave, such as parental, sick, or secondment leave. In a positive development, one in ten roles was reported vacant due to being a newly created role, which is a larger proportion than in previous years when there were just one or two new vacant roles reported.

3.2 Cover arrangements

In some cases, vacancies can be temporarily covered by existing staff, although such staff may not be as qualified and/or available to cover a role fully. Cover staff can be a lower banding or work fewer hours than the staff they are filling in for. To better understand if and how vacant roles are backfilled, the staffing tool collects information about cover arrangements for vacant posts. Of 142 vacant posts in October 2024, 29 were covered (20.4%), with a slightly higher proportion covered in paediatric care compared to adult care (Table 8).

Table 8: Vacancy cover arrangements

	Paediatric Services			Adult Services		
	Covered at ≥ banding & WTE level	Total covered posts	Proportion covered at same level	Covered at ≥ banding & WTE level	Total covered posts	Proportion covered at same level
2022	10	12	83.3%	3	4	75.0%
2023	5	13	38.5%	9	16	56.3%
2024	7	13	53.8%	12	16	75.0%

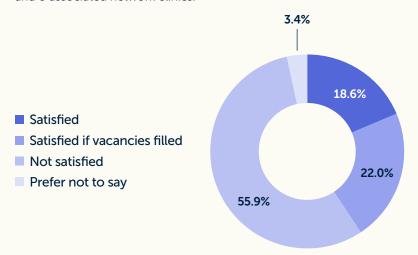
Cover availability varies year-on-year, with only a minority of vacant roles having any cover arrangement in place. Where cover is in place, this is often not at the same level in terms of time or seniority as the vacant role. In October 2024, only 65.5% of vacant roles were covered at the same level as the substantive post. While this is a higher proportion than in previous years, it remains concerning that many vacancies in CF are only partially covered, and most not covered at all, putting additional pressure on remaining staff.

Section 4 Satisfaction with staffing levels

To understand how services perceive their levels of staffing, our staffing tool offers respondents an opportunity to share whether they felt satisfied with the levels of staffing in their service at the time of data collection.

Figure 20: Overall satisfaction with staffing levels in October 2024

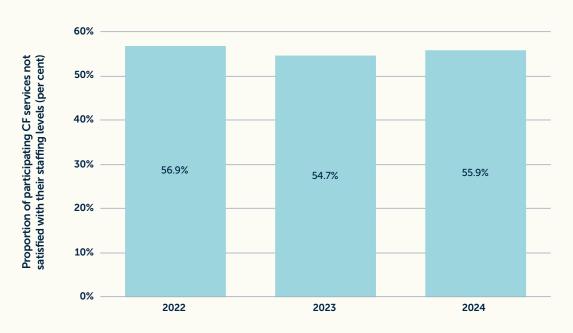
Responses from clinics were counted individually in this calculation; total responses included: 59; 51 CF centres and 8 associated network clinics.



In October 2024, only 11 responding services (18.6%) confirmed they were satisfied with their staffing levels, while 13 (22.0%) said they would be satisfied if their existing vacancies were filled. More than half of participating services (55.9%, n=33) were not satisfied with their staffing (Figure 21).

Figure 21: Proportion not satisfied with staffing levels: 2022, 2023, 2024

Based on responses received from participating services, incl. individual clinics, by year.



Insight: More than half of participating CF services say they are not satisfied with their staffing levels year-on-year.

It is likely that CF services are impacted by ongoing challenges with staffing across the NHS, and some of these findings may be driven by NHS-wide issues with recruitment and retention. Since 2023, a response option in the staffing tool allows services to confirm that they would be satisfied with staffing if all their vacancies were filled. Interestingly, the proportion of services dissatisfied with their staffing remained relatively stable, indicating that staffing challenges within CF teams go beyond issues with vacant roles and that a lack of provision or inadequate provision is impacting satisfaction with staffing in some services.

As paediatric and adult centres serve different populations, it is also important to consider this information individually (Figures 22 and 23).

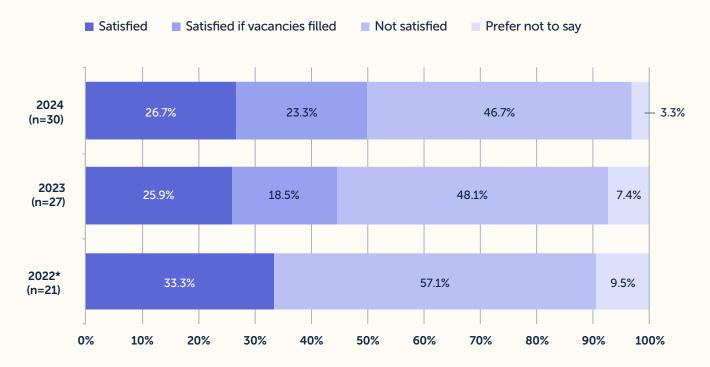
Figure 22: Satisfaction with staffing levels in paediatric services over time

Responses from clinics were counted individually in this calculation, which is why service numbers differ from those in previous sections, where clinic responses had been included under their network centre.



Figure 23: Satisfaction with staffing levels in adult services over time

Responses from clinics were counted individually in this calculation, which is why service numbers differ from those in previous sections, where clinic responses had been included under their network centre.



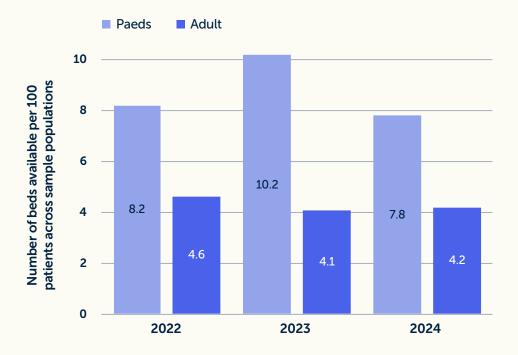
^{*} Response options in 2022 did not include 'Satisfied if vacancies filled', which was introduced as an additional response option from 2023 onwards.

Section 5 Facilities

While modulator therapies have improved the health of many in the CF community, access to suitable inpatient facilities is still critical for high-quality CF care. To maintain infection control, the Standards of Care¹⁹ recommend that people with CF should have their own room with en-suite facilities during inpatient stays. The staffing tool collects data on the number of beds accessible to CF patients, as well as the proportion of these that are en-suite rooms.

Figure 24: Bed availability across sample populations 2022, 2023, 2024

Bed availability is shown as beds available per 100 patients in our sample populations (paediatric and adult), with shared care patients included.

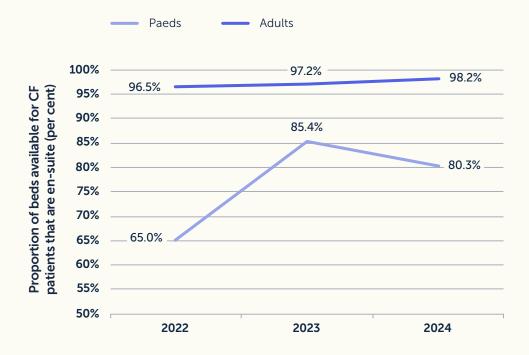


Year-on-year, the number of beds available per 100 paediatric patients was higher than for the adult population (Figure 24). However, beds in paediatric services were less likely to be en-suite (Figure 25).

¹⁹ Cystic Fibrosis Trust, Standards for the Clinical Care of Children and Adults with cystic fibrosis in the UK. 3rd edition, August 2024: cysticfibrosis.org.uk/the-work-we-do/resources-for-cf-professionals/consensus-documents

Figure 25: Proportion of beds available to people with CF that are en-suite

Proportion of beds en-suite out of the total number of beds available across participating CF centres.



Variations in bed availability may be impacted by changes in our sample of CF services or the populations they care for, by temporary closures of wards or refurbishment of facilities, and by other factors, such as bed occupancy rates across NHS Trusts, which can impact on beds available for CF.

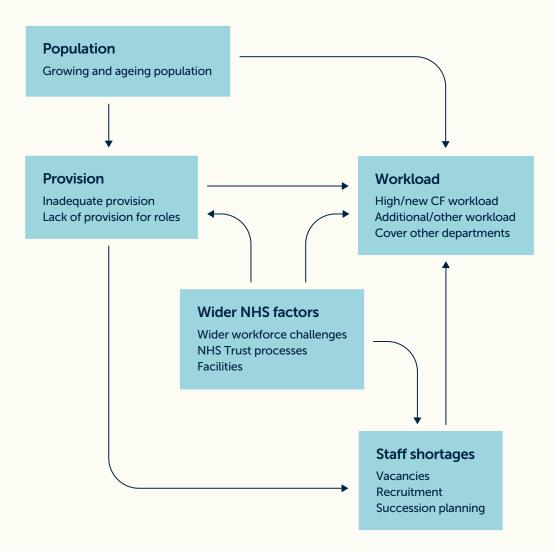
Section 6 Challenges and innovations

In addition to collecting information about the makeup of CF MDTs and bed availability, the staffing tool asks respondents to share reflections on challenges and innovations in their service.

6.1 Staffing challenges

Participating CF centres and some of their network clinics shared specific staffing challenges they were facing, shining a light on several factors affecting satisfaction with staffing levels, many of which lie outside the direct control of CF teams. Figure 24 shows an overview of themes from the analysis of challenges, followed by exemplary quotes for each theme. Quotes are anonymous but disclose service type and, in brackets, the service's perception of its own staffing levels (ie whether or not it was satisfied).

Figure 26: Factors driving staffing challenges within CF teams



In October 2024, provision for roles in CF MDTs was raised as a major challenge by 21 services, both in terms of inadequate provision and or a lack of provision for certain professions. This was particularly, but not exclusively, highlighted for CF pharmacists, psychologists and social workers, for whom workload was also often perceived to have increased.

"Since the introduction of modulators, we haven't had any extra funding or support for this. This has especially impacted our pharmacist who has to screen all modulator prescriptions for the whole region." — Paediatric service (Dissatisfied)

"Shortfall in staffing with doctors and pharmacy, which means Annual Reviews cannot be completed. Shortfall in psychology, which means long waiting lists." – Adult service (Dissatisfied)

"We don't have a social worker but would really benefit from one as the nursing time is frequently spent on social issues." – Paediatric service (Dissatisfied)

"There continues to not be a dedicated psychologist as part of the CF service, instead psychology is accessed by referral to the general health psychology service for children and there is a long waiting time associated with this." – Paediatric service (Satisfied if vacancies filled)

As with previous years, staff shortages, vacancies and issues with recruitment were also frequently cited as challenges. Some services also specifically mentioned concerns around succession planning.

"Recruitment is a problem across most of the MDT but specifically nursing, dietitians and social worker. Positions either receive no applicants or those that do apply aren't suitable. This is causing an increased amount of stress on the nursing staff. It is also having an impact on the services we can offer our patients with the withdrawal of the community service at the current time. Dietitians are now only covering Annual Review clinics due to the shortages." – Adult service (Satisfied if vacancies filled)

"Difficult to recruit into the physio and pharmacy roles. Need more physio support this is a really difficult area because it is hard to recruit into the role, and the physio is often overstretched." – Paediatric service (Dissatisfied)

"We have faced huge challenges in retaining and recruiting psychologists to the CF psychology posts, partly due to under resourcing." – Paediatric service (Dissatisfied)

"Succession planning is a challenge for all posts." – Adult service (Dissatisfied)

As discussed in **Section 3**, the vacancy rate in CF services was slightly higher than the overall rate in the NHS in the final quarter of 2024. There were 142 vacancies across 51 participating CF services, with only a small proportion of these covered.

Several services mentioned internal processes and recruitment freezes as additional challenges when it came to filling existing vacancies.

"We are still waiting for our exercise therapist role to be approved by the Trust. This has resulted in fewer patients having an exercise test at their annual review, and no patients receiving a personalised training programme. This is impacting on the engagement of patients with exercise and all its benefits." – Adult service (Dissatisfied)

"Our Band 4 administrator is vacant (our Trust does not readvertise until a post has been vacant for 16 weeks as a cost-cutting measure)." — Paediatric service (Satisfied if vacancies filled)

"We had a Band 6 post vacant for over 6 months, this was due to management/recruitment approving the funding, this has now been filled and will make a difference to the nursing workload." – Adult service (Satisfied)

Unsurprisingly, with limited provision and workforce shortages, including across the wider NHS, another common challenge area was workload for existing staff.

"CF CNS case-manage the whole patient group to ensure they are on the correct pathways of care from NBS [New Born Screening], late diagnosis, admission & discharge planning, home IVs, CFTRm initiation, education and monitoring, joint outreach clinics, home care service, annual assessment and transition to adult CF care. As such there is little time to meet other aspects of CNS specific roles, such as educational resources, support groups, study days/educational meetings for support and network staff, QI and audits." – Paediatric service (Dissatisfied)

"Our social worker has to cover both CF adults and CF paediatrics. This is incredibly challenging, and she is overstretched covering both services. Social work support can be very complex and time consuming, often involving long visits to patients' homes, meetings with employers/college representatives and attending court hearings." – Adult service (Dissatisfied)

Several services reported staff taking on additional workload and covering for other departments or specialties.

"Physio team also cares for a large bronchiectasis service – increasingly pulling the physio team from CF provision. Physio team understaffed and under banded despite growth in both services, putting the physiotherapy service at risk." – Adult service (Dissatisfied)

"All staff cover bronchiectasis in addition to CF and the bronchiectasis workload is ever increasing."

— Paediatric service (Satisfied if vacancies filled)

"One challenge is being able to use our team in the most efficient way, such as community working. Currently we struggle to get agreement from management to do this. Our CF inpatient ward continues to be managed by our team, yet our beds are often filled with general respiratory and general internal medicine patients which uses our resources." – Adult service (Satisfied if vacancies filled)

"Our specialist CF pharmacist is having to cover gaps in general paediatric pharmacy cover due to a vacant post so is not able to fulfil the job requirements." — Paediatric service (Satisfied if vacancies filled)

Insight: CF teams face several staffing challenges, with many citing inadequate provision as a key issue, alongside staff shortages, recruitment challenges and high workloads.

6.2 Service innovations

Many CF centres and teams adapt and innovate to mitigate or overcome staffing and other challenges to deliver the best possible care for people with CF. Our analysis of free text comments in the staffing tool identifies a number of different approaches to addressing staff shortages and other arising challenges. Mitigating actions taken range from developing existing staff and introducing new roles to delivering more virtual, home and community care.

Figure 27: Staffing innovations and mitigations used by CF teams

Staff and wider team

- Non-medical prescribers
- Expanded and advanced practice roles
- New and emerging roles
- Network/shared care meetings
- Collaborating beyond CF team

Specific programmes

- Transition clinics
- Commit to fit for teenagers
- Remote 'Bone Building Camp'
- Joint initiative for bone health
- Coffee mornings
- Dietetic education and cooking classes
- 'Underserved MDT'

Care delivery

- Adapting clinic appointments
- Virtual care / Attend Anywhere
- Home and community care
- Independent clinics
- Improved Facilities / Access
- Improved/streamlined processes
- Using new tests or screening

Other activities

- Quality improvement
- Research
- Clinical trials

Insight: CF services across the UK continue to adapt and innovate to mitigate staffing challenges and meet the needs of their patients. Key innovations include developing existing staff and adapting how care is delivered, though despite these innovations, staffing often remains a challenge.

Staff and wider team

Developing existing members of the CF MDT plays an important part in addressing staffing challenges. In October 2024, more than half the responding CF centres (28 of 51) specifically mentioned having non-medical prescribers or staff training to become non-medical prescribers.

"Pharmacist independent prescriber and in clinics managing CFTR modulator prescribing."

- Paediatric service (Dissatisfied)

"We now have two pharmacist non-medical prescribers (NMP) and one nurse has completed the NMP course in September. We also have one CF nurse who has recently completed the "Specialist Nurse" course and is embarking on the NMP course in January." – Adult service (Satisfied if vacancies filled)

"Our physio is now an AHP [Allied Health Professional] prescriber and is assisting with the prescriptions for nebuliser trials." – Adult service (Dissatisfied)

Distributed prescribing responsibilities offer an effective way to reduce reliance on doctors and can make prescribing more efficient. Due to the specialised nature of CF care, use of non-medical prescribers may be more common in CF than in other fields.

CF services also described developing existing staff in other ways, such as advanced practice qualifications, or embedding new roles within the CF MDT, such as youth workers, diabetes staff and benefits advisors.

"Advanced practice in the MDT including requesting radiology, bloods, etc." – **Adult service** (Dissatisfied)

"Rather than 2x social workers we have 1 x social worker and 1 x youth worker. Within the administrative team, more cross-working and cover of each other's role." – Adult service (Satisfied)

"We have recently recruited a new Band 5 pharmacy technician to assist with demands on current 8a pharmacist, related to management of precision medications. We appointed an additional Band 3 administrator to give additional support to the shared care appointments." – Paediatric service (Satisfied)

"New post as CF occupational therapist. We also have a diabetes consultant who does sessions in CF diabetes, and musculoskeletal physiotherapists who do sessions in CF." – Adult service (Satisfied)

Additionally, many CF services also work closely with other relevant specialties, and several mentioned joint clinics or meetings with other teams as innovations supporting quality of care.

"Set up a joint meeting with the diabetic team- aiming for quarterly meetings."

- Paediatric service (Dissatisfied)

"A pharmacist is going to join team meetings and help with prescribing issues."

- Paediatric service (Dissatisfied)

"Establishing links with cardiology services to formalise cardiometabolic risk pathways."

- Adult service (Dissatisfied)

Changes to care delivery

CF services are adapting care delivery to meet the diversifying needs of their patient populations.

- "We are exploring whether patients would want video and evening clinics again."
- Adult service (Satisfied)

"Service evaluation and feedback exercise completed, and this has informed approach to follow up in the post-modulator and post-COVID era, such as frequency of appointments, face to face vs. telemedicine, etc." — Paediatric service (Satisfied if vacancies filled)

"Young people stable on CFTR modulators have been able to have their routine clinic visits spaced to three-monthly." – Paediatric service (Satisfied if vacancies filled)

Some CF services had expanded home and community care offers, including remote monitoring, virtual wards and home visits.

"Virtual Ward for CF": provides hospital-level care at home for people with CF receiving intravenous antibiotics. Their progress on the virtual ward is recorded in the electronic record system. They have direct access for admission to the in-patient ward at any time. They have scheduled virtual consultations with the CF multidisciplinary team and are discussed at the weekly MDT meeting."

– Adult service (Satisfied)

"Physiotherapists go to the patients' house/school for daily airway clearance and exercise sessions to support acutely unwell patients." — Paediatric service (Satisfied if vacancies filled)

Several other changes to care delivery were mentioned, including implementation of new tests or screening, often related to the use of modulator therapies.

"Introduction of bioelectrical impedance measurements for assessment of lean body mass / fat mass for children commencing on triple modulator therapy, to allow for bespoke dietary advice based on changes to body compartments." – Paediatric service (Dissatisfied)

"We have set up newborn cataract screening of babies born to mothers who are taking Kaftrio." – Adult service (Dissatisfied)

Specific, targeted innovations and mitigations

Several participating services had implemented targeted interventions for specific groups, such as transition clinics or educational initiatives.

"Joint initiative CF dietitians and physiotherapists targeting patients identified at highest risk CF related bone disease. Six-week virtual program with dietary advice and exercise." – Paediatric service (Dissatisfied)

"We have developed the transition service. We now hold four clinics within the adult setting for patients from the age of 16 up." – Paediatric service (Dissatisfied)

"We hold regular coffee mornings for families throughout the year, allowing them to meet other families. This also involves a cooking class." – Paediatric service (Dissatisfied)

"We have established dietetic education clinics." - Adult service (Satisfied)

"We have started a weekly underserved MDT meeting (hard-to-reach patients), from this we are tailoring community working within the restraints of our management." – Adult service (Satisfied if vacancies filled)

Quality improvement and research

Adult services in the staffing tool specifically confirmed they use quality improvement to continually develop their service. Several sites also actively support research and clinical trials, although some do not have dedicated capacity for this.

"Embedding of QI with designated QI leads. In collaboration with paeds team, improvement to transition pathway from paeds to adult services. Exploring potential for youth worker role as part of this work." – Adult service (Dissatisfied)

"Various research studies are being carried out including the mRNA trial and the insulin pump study. Weekly QI meetings are continuing to review service/systems." – Adult service (Satisfied if vacancies filled)

"CF team fulfil the research team duties including clinical study investigations and data entry to ensure our patients still have access to clinical trials." – Adult service (Dissatisfied)

Recommendations and next steps

UK-wide recommendations

Engagement with the staffing tool has remained high despite increasing staffing pressures across the NHS, with a record 51 of 58 CF centres contributing in 2024. Findings from our Patient-Reported Experience Measures²⁰ show that CF teams are still delivering high-quality care, but our staffing tool data clearly shows they continue to be stretched. With vacancy rates above NHS-wide levels, there are staffing gaps in several CF services, and we have repeatedly found that not every CF team includes the core roles recommended in the Standards of Care. There is also little resilience to cover staff absences, particularly for psychosocial and pharmacy staff, for whom there is often just one role available in a CF team.

Paediatric and adult services have different staffing configurations and face diverse staffing challenges. Consideration of service type, size and population is important when trying to address staffing challenges at local and regional levels. Furthermore, each centre's staffing data should ideally be considered in the context of the care model in use, relevant best practice guidelines, and complementary intelligence, such as data on patient experiences and outcomes.

However, from insights provided by the staffing tool in 2024 and previous years, we can make some general recommendations that apply across the UK. Using these insights, Cystic Fibrosis Trust will continue to support efforts to ensure all people with CF have access to a full multidisciplinary team of CF professionals.

- Sufficient resourcing of CF services is critical to ensure staffing levels are adequate to meet the evolving and diversifying needs of the CF community. We will continue to advocate and campaign for this, working with the community to ensure their views and feedback are heard.
- Exploring issues around staff recruitment and retention at national level is important to address vacancy challenges and gaps in provision. We have begun joint work with the UK Psychosocial Professions in CF (UKPPCF) group to explore what is driving gaps in psychology and social work. While the reasons are multifactorial, a better understanding will inform projects to tackle some of the key challenges with psychosocial staffing.
- Continuous monitoring of staffing levels in CF centres and across the CF population as a whole is warranted to understand how these change over time and to identify early trends that could impact CF care delivery. We will keep monitoring this annually with our staffing tool.
- Many services innovate to address staffing challenges and should continue to be encouraged to share learning from the changes they made with others. We will continue to facilitate peer-to-peer learning through our events and materials for CF professionals.²¹

²⁰ Cystic Fibrosis Trust, Patient-Reported Experience Measures; 2024 cysticfibrosis.org.uk/QI

²¹ Cystic Fibrosis Trust, Support for CF professionals; 2025 cysticfibrosis.org.uk/about-us/cf-clinicians-how-we-can-help-you

Service-level recommendations

All CF centres that contributed to the staffing tool are issued with a bespoke data summary showing staffing and vacancy levels in their centre or network, compared to average levels from across the full sample. CF MDT staff can review the full report alongside their bespoke centre-level summary.

When exploring staffing challenges, consideration should also be given to the needs of a centre's population, which may also change over time, particularly with the increasing availability of modulator therapies. This could be facilitated by regularly capturing and reviewing patient outcomes and experiences, for instance, through ongoing contributions to the Trust's UK CF Registry and participation in the staffing tool, as well as future cycles of patient-experience surveys.

If a service identifies any specific issues with their staffing levels, it is important to consider the underlying cause of any shortages in order to address them. For example, a lack of funding for posts needs to be tackled differently to issues with recruitment to existing but vacant posts. A service might also be fully staffed for some professions but lack others entirely.

Depending on local needs and challenges identified, CF centres could consider steps they could take to address these. For example:

- if a centre has longstanding vacancies in a profession and is struggling to recruit to these posts, it could review the recruitment process, including job descriptions and how roles are advertised, seeking advice from professional bodies such as the UK CF Medical or Nursing Association, or UK Psychosocial Professions in CF, to attract candidates.
- if a centre has recognised that it needs additional funding for new posts, it could use evidence from its staffing summary and the full sample findings, in addition to other intelligence, to develop a business case.
- if a centre has identified specific pressures, it could explore innovative solutions to relieve some of these pressures, for example;
 - use of virtual and joint clinics and meetings to reduce travel time
 - upskill existing staff to become non-medical prescribers to reduce pressure on existing prescribers
 - increase provision of services such as remote monitoring and home IVs in the community to relieve pressures on inpatient facilities
 - use alternative roles to deliver some aspects of care, to free up specialist CF staff time for more specialised aspects of care.

Our next steps

Cystic Fibrosis Trust is uniting for a life unlimited for everyone affected by cystic fibrosis. Timely access to CF specialist staff is crucial to help ensure people with CF are supported to manage the physical challenges and mental pressures of CF so they can live a fulfilled life.

Cystic Fibrosis Trust will continue to work with CF centres to explore and address staffing challenges at a local level. For example, we support data deep-dives, facilitate planning of targeted quality improvement activities, or advise on business cases based on data insights. Depending on the specific challenges a service is experiencing, existing resources and support offered by Cystic Fibrosis Trust will also be relevant and helpful²².

Cystic Fibrosis Trust has a range of support services for people living with CF and their families that CF centres can signpost to.

- **Helpline** practical support and information via our Helpline at **cysticfibrosis.org.uk/helpline**, email **helpline@cysticfibrosis.org.uk**, call 0300 373 1000 or WhatsApp on 07361 582053.
- **Grants** a range of welfare grants to help people with CF in times of financial need, including for emergencies, transplant assessments, health and wellbeing, education, prescription prepayment certificates (PPC) and funerals. **cysticfibrosis.org.uk/grants**
- Benefits support and income maximisation service financial entitlement checks and support with applying for benefits, such as DLA, PIP or Universal Credit. cysticfibrosis.org.uk/benefits
- **Youth programme** a dedicated programme of events and activities for children and young people with CF and their siblings. **cysticfibrosis.org.uk/CFyouth**
- **CF Forum** an online space to connect with others living with or affected by CF. **forum.cysticfibrosis.org.uk**
- CF Connect peer support service for parents of children with CF. cysticfibrosis.org/cfconnect
- Work Forwards one-to-one support from employment experts, support with employment rights, and group sessions to learn key employability skills. cysticfibrosis.org/workforwards
- **Helen Barrett Bright Ideas Awards** to help people with cystic fibrosis turn their hobbies into new businesses. **cysticfibrosis.org/hbbi**

We will continue to monitor staffing levels in CF centres through our staffing tool and will publish our findings to help identify trends, changes and challenges, and to share the innovative approaches centres use to ensure they can provide the best possible care for people with CF. We will also continue to improve and update the staffing tool and welcome feedback.

You can contact the Quality Improvement team at Ql@cysticfibrosis.org.uk

Glossary

Word/phrase	Meaning
Centre	Hospital providing expert care and specialised disease management to people living with cystic fibrosis
CF	Cystic fibrosis
CFTR modulators	CFTR modulators and modulator therapies, also known as 'precision medicines', work to tackle the underlying cause of cystic fibrosis (<i>ie</i> the underlying genetic mutations) by helping to make the CFTR protein work effectively
Clinic	Regional hospital or site where treatment is provided locally for people with CF; clinics are linked to a centre hospital / CF team via a Network
CNS	Clinical Nurse Specialist
Community support	Care that is delivered locally, <i>ie</i> in the community or at your home
CF Service Specification	Standards of care issued by NHS England that adult and paediatric CF centres in England are working to
FTC	Fixed-term contract, a time-limited type of employment
Home IVs	Intravenous antibiotic therapy given in the patient's home
Median	The middle value (number) when all values in a series are arranged from smallest to largest
MDT	Multidisciplinary team; your CF team made up of each discipline <i>ie</i> nurse, physio, social worker, dietitian, <i>etc</i>
Network	A CF centre and its linked clinics form a Network
PREMs	Patient-Reported Experience Measures
QI	Quality Improvement – a framework to systematically improve the ways care is delivered to patients
QI WG	Quality Improvement Working Group – a group of health professionals and people with CF/family members helping the Trust's QI team to work to improve the way CF care is delivered
Range	Smallest to largest value in a series
Standards of Care	3rd edition of Cystic Fibrosis Trust's recommended best practice guidelines for CF services (published August 2024)
WTEs	Whole Time Equivalents (also sometimes called 'Full Time Equivalents'; FTEs)



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.