Cystic Fibrosis Trust

UK Cystic Fibrosis Service Resourcing 2021 to 2023

Based on findings from the annual Cystic Fibrosis Trust staffing tool

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Uniting for a life unlimited

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Cystic Fibrosis Trust

UK Cystic Fibrosis Service Resourcing

2021 to 2023

Contents

Summary

Participation

In October 2023, 46 of 60 CF centres across the UK completed the staffing tool. This included 23 paediatric and 23 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 2021, 2022 and 2023), focused mainly on data from October 2023.

Key insights

- 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 workers, pharmacists and clinical psychologists:
  - 25 of 46 participating CF centres (54%) reported not having any active CF specialist social workers in their MDT.
  - 8 of 46 participating CF centres (17%) reported not having any active CF pharmacists in their MDT.
  - 5 of 46 participating CF centres (11%) reported not having any active CF clinical psychologists in their MDT.
- A slightly larger proportion of paediatric CF services appear to lack certain staff groups in their MDT compared to adult CF centres, which have a much higher number of vacancies.
- Some services have additional staff, not funded from CF budgets.
- In October 2023, median staff time available in paediatric centres was similar compared to adult centres in our sample for most staff groups; however, several CF centres reported gaps in certain staff groups, and there continues to be a lot of variation in staffing levels and availability between centres.
- Overall staff time available to the CF population across participating centres fluctuates, and it will be vital to monitor this in future.
- 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 2023, the vacancy rate in participating CF centres was higher than the NHS vacancy rate overall at 12.2% versus 7.6%.
- A slightly higher proportion of vacancies in CF centres for children remained unfilled for six months or longer, while centres for adults reported a higher number of vacancies.
- Satisfaction with staffing levels among responding services remained relatively low year-on-year, with only a fifth saying they were 'satisfied' with staffing in their service in October 2023.
- CF teams face staffing challenges, both as a result of ongoing staff shortages in the NHS as a whole, as well as novel treatments for CF that have led to increases in life expectancy and shifts in the care needs of the CF community.
- CF services continue to adapt and innovate to mitigate staffing challenges and meet the needs of their patients. Key innovations include developing existing staff or new roles and implementing new approaches to care delivery, though, despite these innovations, staffing often remains a challenge.

Introduction

People with cystic fibrosis (CF) living in the UK receive care from a range of healthcare teams and services, including specialist CF multidisciplinary teams (MDTs). These MDTs are made up of different specialist CF health professionals, 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 Care[1] and NHS England's CF Service Specifications for Children and Adult services[2,3] provide consensus guidance on the composition of CF MDTs, as well as recommended qualifications and banding of MDT staff, although it is worth noting that both are expected to be updated in 2024.

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 2012 to 2022, the proportion of people with CF aged 16 or over increased, with the median age of the CF population in 2022 at 22 years[4]. Furthermore, the median predicted survival age has increased steadily, so that half of the children born with CF in 2022 are now predicted to live well into their fifties.

To continue this trend of ongoing improvement, it is essential to ensure that CF centres have sufficient staff 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 multi-system 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. Additionally, cost of living pressures could result in increased demand for financial and benefits advice, as well as mental health and crisis support. High-quality CF care, therefore, requires appropriate resourcing for all specialties 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 in the NHS generally[5,6,7].

Cystic Fibrosis Trust seeks to ensure that people with CF can 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. 2nd edition; 2011, last update 2022: **www.cysticfibrosis.org.uk/the-work-we-do/resources-for-cf-professionals/consensus-documents**

2 NHS England, Service Specification A01/S/b Cystic Fibrosis Children; 2018: **www.england.nhs.uk/wp-content/uploads/2018/07/a01Sb-spec-cystic-fibrosis-child.pdf**

3 NHS England, Service Specification A01/S/a Cystic Fibrosis Adults; 2018: **www.england.nhs.uk/wp-content/uploads/2018/08/Cystic-fibrosis-adult.pdf**

4 UK CF Registry Annual Report 2022, published Sep2023: **www.cysticfibrosis.org.uk/registryreports**

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

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

7 Nuffield Trust, Waste not, want not: Strategies to improve the supply of clinical staff to the NHS, Sep 2023: **https://www.nuffieldtrust.org.uk/research/waste-not-want-not-strategies-to-improve-the-supply-of-clinical-staff-to-the-nhs**

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 (2021-2023). 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 introduced to increasing proportions of the population, alongside dramatic changes in digital health offerings[8,9] 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 2023 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 patient population, access to support from the community and other non-CF health professionals, such as GPs, as well as additional factors that could impact on staff cover needed.

Data collection and limitations

Each year since 2019, Cystic Fibrosis Trust has invited all specialist CF services to complete our dedicated 'staffing tool' to share detailed information about staff groups, contract types, banding, vacancies and satisfaction with staffing levels. The tool collects this information directly from CF services via the 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 varied year-on-year. Clinics that enter their own Registry data can individually contribute to the staffing tool, but responses are combined with their network centre in analyses.

Over 70% of CF centres in the UK contribute to the staffing tool most years, but we do not have staffing information from all active CF services. This report is based on data collected from 46 of 60 CF centres (76.7%) in the UK in October 2023 and also draws on staffing data from previous years, which were based on slightly different numbers and combinations of centres (Table 1). While there is some overlap in the sample year-on-year (n=30), the number of participating services varied, and some services contributed data in just one or two years.

8 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

9 Gov.uk, Cystic fibrosis drugs Kaftrio and Kalydeco licensed for patients aged two to five years old, Nov 2023: **https://www.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*

	2021	2022	2023
Paediatric centres & population	**81.3% (26 of 32)** Full care: 2,303 Shared care: 1,485	**78.1% (25 of 32)** Full care: 2,543 Shared care: 1,437	**71.9% (23 of 32)** Full care: 2,155 Shared care: 1,051
Adult centres & population	**82.1% (23 of 28)** Full care: 5,655 Shared care: 166	**64.3% (18 of 28)** Full care: 3,555 Shared care: 239	**82.1% (23 of 28)** Full care: 5,828 Shared care: 151
Total centres	**81.7% (49 of 60)** Full care: 8,716 Shared care: 1,651	**71.7% (43 of 60)** Full care: 6,970 Shared care: 1,676	**76.7% (46 of 60)** Full care: 7,983 Shared care: 1,202

*Population figures show full care as well as shared care 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 the CF team

The data collected constitute a snapshot of staffing resources available within CF centres at a specific 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 with regard to the impact of temporary vacancies on staff availability. The picture will be different at other times of the year, and data are not representative of staffing in CF services over a year.

Staff time in this publication is usually described as Whole-Time Equivalents (WTEs) per 75 patients to enable comparison of staffing levels across CF centres of differing sizes. Average WTE levels presented are purely based on staffing tool data submitted to Cystic Fibrosis Trust by participating CF services. They do not indicate a recommended or desired level of staffing and do not imply that services at or above the average WTE level are sufficiently staffed.

Furthermore, when considering staffing levels presented in this report, a direct comparison of these to the proposed levels in the Standards of Care[10] is not recommended. The current Standards' WTE recommendations suggest slightly different staffing levels for differently sized services and note that staffing levels do not necessarily have to change incrementally with patient numbers. There are also a number of other factors, including shared care arrangements and the service model, that need to be taken into account when exploring what level of staffing is appropriate in a service. Additionally, the current Standards focus on CF specialist staff working in the MDT, while this report focuses on staff funded through CF budgets who are providing services to people with CF. This report can, therefore, include roles such as healthcare assistants and welfare advisers not covered by the Standards of Care. Conversely, some teams will also have access to other specialist staff, not funded through CF budgets, who contribute to the CF MDT, and such staff would not be captured within the staffing tool WTE figures. However, this report includes information about the number of CF centres that have additional staff who are not funded from the CF budget and provides an overview of the specialties such roles fall into.

Collecting accurate CF team staffing information can be difficult 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

10 Cystic Fibrosis Trust, Standards for the Clinical Care of Children and Adults with cystic fibrosis in the UK. 2nd edition; 2011, last update 2022: **www.cysticfibrosis.org.uk/the-work-we-do/resources-for-cf-professionals/consensus-documents**

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 specialties, 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. 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 clinics 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 CF 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.

We continuously work to improve how we capture and report information on staffing resources, bed availability, as well as full care versus shared care patients, to make our staffing information more accurate. For example, we now 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 **QI@cysticfibrosis.org.uk**

Section 1
Staff groups available in CF MDTs

The staffing tool asks services to provide details about members of their multidisciplinary team (MDT) to better understand which specialisms are providing input into CF MDTs and are available to support people with CF. Most staff in CF MDTs are funded through CF budgets, and the staffing tool focuses on such staff. However, section 1.1 provides an overview of additional staff available in CF MDTs whose roles are funded through other means.

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 specialism. "Active staff" include substantive post holders and cover staff available to input into the CF MDT. This does not mean these centres were sufficiently staffed in these staff groups; it merely confirms whether input or support from the respective specialism was available in a centre's CF MDT. Section 2 (Staffing Configurations) provides further detail on available staff time across the different groups.

Table 2: Proportion of participating paediatric centres that had at least one active member of staff in each group

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

	October 2021		October 2022		October 2023	
	Percent	Centres	Percent	Centres	Percent	Centres
Medical (Doctors)	100%	26 of 26	100%	25 of 25	100%	23 of 23
Nursing	100%	26 of 26	100%	25 of 25	100%	23 of 23
Physiotherapy	100%	26 of 26	100%	25 of 25	100%	23 of 23
Dietetics	100%	26 of 26	96.0%	24 of 25	100%	23 of 23
Psychology	76.9%	20 of 26	80.0%	20 of 25	87.0%	20 of 23
Social Work	30.8%	8 of 26	32.0%	8 of 25	39.1%	9 of 23
Pharmacy	80.8%	21 of 26	88.0%	22 of 25	73.9%	17 of 23
Administrative	84.6%	22 of 26	92.0%	23 of 25	91.3%	21 of 23
Research	30.8%	8 of 26	44.0%	11 of 25	44.0%	8 of 23
Other	19.2%	5 of 26	20.0%	5 of 25	30.4%	7 of 23

Table 3: Proportion of participating adult centres that had at least one active member of staff in each group

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

	October 2021		October 2022		October 2023	
	Percent	Centres	Percent	Centres	Percent	Centres
Medical (Doctors)	95.7%	22 of 23	100%	18 of 18	100%	23 of 23
Nursing	95.7%	22 of 23	100%	18 of 18	100%	23 of 23
Physiotherapy	95.7%	22 of 23	100%	18 of 18	100%	23 of 23
Dietetics	95.7%	22 of 23	100%	18 of 18	100%	23 of 23
Psychology	82.6%	19 of 23	72.2%	13 of 18	91.3%	21 of 23
Social Work	56.5%	13 of 23	33.3%	6 of 18	52.2%	12 of 23
Pharmacy	87.0%	20 of 23	100.0%	18 of 18	91.3%	21 of 23
Diabetes	Not included		44.4%	8 of 18	43.5%	10 of 23
Administrative	91.3%	21 of 23	100.0%	18 of 18	100%	23 of 23
Research	65.2%	15 of 23	50.0%	9 of 18	56.5%	13 of 23
Other[11]	43.5%	10 of 23	61.1%	11 of 18	60.9%	14 of 23

Nearly all participating CF centres confirmed their MDT included CF specialist medical, nursing, physiotherapy, and dietetics staff. This is crucial because these staff groups are also the groups that people with CF say they need to access the most[12]. However, other expertise important for holistic CF care was not always available, for example because of vacancies. This means some people with CF may struggle to access certain specialist staff when they need them.

While most paediatric services confirmed they had CF specialist medical, nursing, physiotherapy, and dietetics staff, not all children with CF and families had input from and access to CF specialist psychologists, social workers and pharmacists, whose availability could change year-on-year and varied between centres (Table 2). The proportion of paediatric centres with specialist CF social worker input was particularly low year-on-year. This does not necessarily mean that families under the care of centres without specialist CF social worker input cannot access social support. Centres may refer to Social Welfare Advisors or similar roles, or they may work with social services in the community. However, specialist CF social workers bring expertise and knowledge of the condition that is valued by people with CF.

Similar to services for children, all participating adult centres confirmed that their MDT included CF specialist medical, nursing, physiotherapy, and dietetics staff in October 2023 (Table 3). Access to CF specialist psychologists, pharmacists and social workers was variable in adult services, though better than in paediatric services. Ten of 23 adult CF centres (43.5%) said they had dedicated diabetes staff.

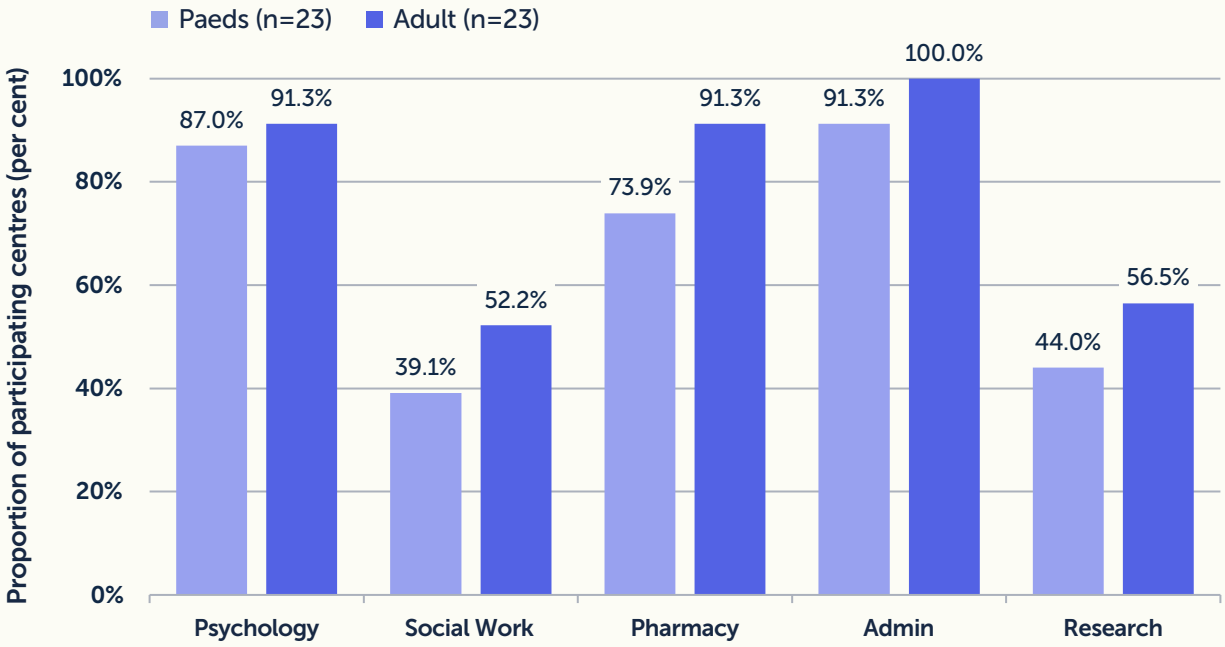
Insight: Not all people with cystic fibrosis consistently have access to a full multidisciplinary team at their CF centre, particularly when it comes to CF specialist psychology, social work, and pharmacy.

11 "Other" group includes roles such as: Welfare Advisors, Youth Workers, Activity Coordinators, CF Practitioners, Microbiologists, Physiologists and Exercise Therapists

12 Cystic Fibrosis Trust, Patient-Reported Experience Measures; 2023 **www.cysticfibrosis.org.uk/QI**

When comparing the availability of staff groups between paediatric and adult services, there was a slightly higher proportion of centres for adults reporting access to psychosocial, pharmacy, administrative and research staff in their CF MDTs. In October 2022, a lower proportion of participating adult centres had said they had access to CF psychologist input (72.2% of adult centres vs. 80% of paediatric centres) due to a high number of vacancies in this staff group in adult services at the time. Reassuringly, in the latest data from 2023, there were fewer psychology vacancies, and more participating adult CF centres confirmed that they had psychology input available. However, the availability of CF specialist social work in both adult and paediatric care is still variable, with only 21 of 46 participating centres (45.7%) overall confirming access to CF social work staff in their CF MDT in October 2023. 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 and more[13].

Figure 1: Proportion of paediatric and adult CF MDTs with active psychology, social work, pharmacy, administrative and research staff in Oct 2023



Availability of psychologists, social workers, pharmacists, administrators, and research staff was more easily impacted by vacancies compared to the other staff groups. This is because there was usually only one role in each of these groups within each centre, which offers limited resilience when staff leave, retire, or take time off. When the only role available is vacant, there is no input from this staff group into the CF MDT unless appropriate cover is in place. Some services also reported that they did not have such roles within their CF MDT.

It is important to understand whether apparent gaps in staffing are due to open vacancies or to there not being roles for such staff within CF MDTs. Figure 2 provides an overview of the proportions of participating CF centres that had each specialist staff group available in the MDT, alongside the proportion that lacked input from these staff groups. The latter group is split into whether there were roles available in a centre that were vacant in October 2023 or whether there were no roles available in a centre at all.

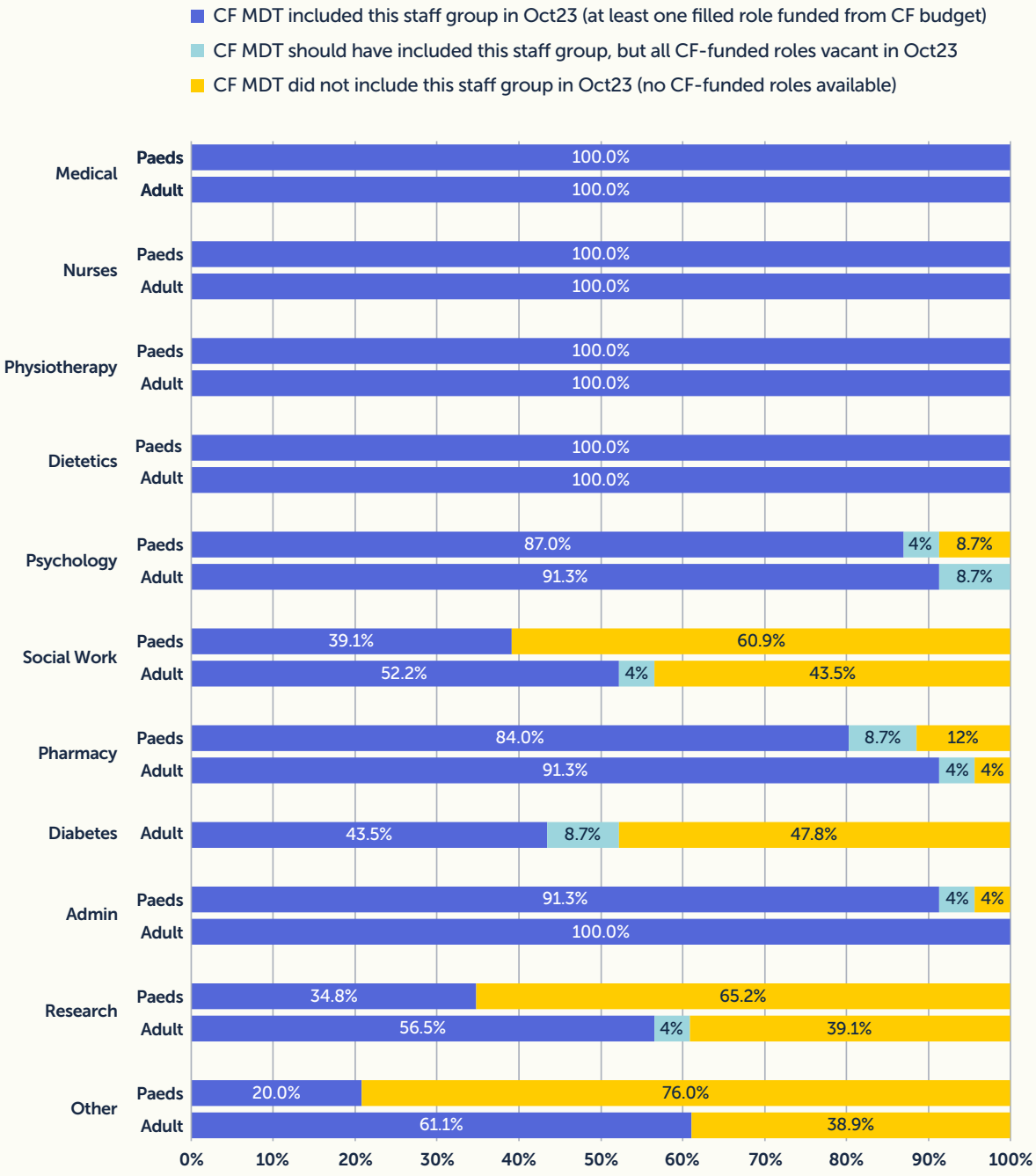
This analysis shows all participating adult centres had roles available for CF psychologists, though two adult centres (8.7%) temporarily lacked input from this staff group due to these roles being vacant. It also shows that one participating adult CF centre lacked specialist CF social worker input in the short term, as they had an open vacancy, while ten adult centres (43.5%) had no roles for CF social workers available. Services for

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

children were generally less likely to have any CF-funded roles available for specialist psychosocial staff in their MDTs, with two (8.7%) services not having any roles for psychology and 14 (60.9%) not having any roles for social workers supported from CF budgets.

Figure 2: Availability of staff groups in CF MDTs

NB: The below is based on data from participating paediatric (n=23) and adult (n=23) CF centres and focuses on roles funded from centres' CF budgets only; occasionally CF MDTs may have additional staff not funded from CF budgets who would not be included here (see section 1.1)



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

1.1 Additional staff

In 2023, the Staffing Tool asked participating CF centres if they had access to any additional staff who were not funded from CF budgets. Where this was the case, the tool then explored which additional roles were available to understand if some of the gaps identified might be covered by staff funded from non-CF budgets who were feeding into CF MDTs.

Eighteen participating centres had additional staff available in at least one staff group: eight of 23 paediatric centres (34.8%) and 11 of 23 adult centres (47.8%). Ten of these centres had roles in more than one group in their CF MDT, which were not funded from the centre's CF budget. Most commonly, additional roles were for diabetes or research staff (Table 4).

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

NB: The below shows the number of participating centres with additional staff available within the CF MDT who were not funded from the centre's CF budget

Non-CF funded staff	Paediatric centres with non-CF funded staff	Adult centres with non-CF funded staff
Medical (Doctors)	2 of 23	3 of 23
Nursing	0 of 23	0 of 23
Physiotherapy	1 of 23	2 of 23
Dietetics	0 of 23	0 of 23
Psychology	0 of 23	1 of 23
Social Work	0 of 23	1 of 23
Pharmacy	1 of 23	2 of 23
Diabetes	4 of 23	5 of 23
Administrative	0 of 23	0 of 23
Research	4 of 23	3 of 23
Other	3 of 23	1 of 23

Additional staff in clinical psychology and social work were rare. No paediatric centres reported access to such staff, and only two adult centres said they had input from psychosocial staff not funded from the CF budget. The centre with an additional social work role had not reported any CF-funded roles for social workers. Therefore, this brings the number of adult CF centres with social worker input in the CF MDT to 13 of 23 (56.5%; Table 3). In contrast, the centre with additional psychologist input also had a CF-funded psychology role, therefore not impacting on the gaps identified in psychology. Three centres in the staffing tool also reported pharmacy staff not funded from CF budgets, though two of these also had CF-funded pharmacy roles available. Therefore, while access to additional staff will often be beneficial to CF teams, such staff do not appear to fill the gaps in psychosocial and pharmacy staffing identified in Tables 2 and 3.

Insight: Some CF MDTs include additional roles that are not funded from CF budgets but that deliver care for people with CF. Access to such roles varies.

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, characteristics of the patient population, and other factors, such as access to support and services in the community. However, it is important to monitor staffing levels within CF services, as these can be linked to the ability to meet professional standards and improve clinical outcomes. Staffing information provides important insights to help teams explore whether the level of staffing in their service is adequate and to track how it changes over time.

To compare staffing levels across centres of differing sizes, we use the total Whole-Time-Equivalents (WTEs) available within each staff group at a centre and work out the centre's WTEs per 75 patients from this. This approach is aligned with the current Standards of Care[14] and takes into account that centres serve different numbers of people and, therefore, require different staffing levels to take care of their population. Calculating WTE per 75 patients provides us with a figure that can be compared more easily, though this does not adjust for any other factors.

Table 5: Median centre-level staff time available by staff group in Oct 2023

NB: The table below shows the median WTE available per 75 patients in participating paediatric and adult centres in October 2023; vacant roles are not included in this calculation 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 in the table below to ensure the table only includes staff actually available within services at the time

	Paeds Services (n=23)		Adult Services (n=23)	
	Median* WTE / 75 patients	**Range** Lowest - Highest**	**Median* WTE / 75 patients**	**Range** Lowest - Highest**
Medical (Doctors)	0.8	(0.3 – 2.0)	0.7	(0.4 – 1.4)
Nursing	1.6	(0.8 – 2.7)	1.3	(0.5 –2.4)
Physiotherapy	1.2	(0.5 – 2.5)	1.0	(0.5 – 2.9)
Dietetics	0.6	(0.4 – 1.4)	0.4	(0.2 – 0.7)
Psychology	0.3	(0.0 – 0.9)	0.3	(0.0 – 1.5)
Social Work	0.0	(0.0 – 0.8)	0.1	(0.0 – 0.7)
Pharmacy	0.2	(0.0 – 1.1)	0.3	(0.0 – 0.8)
Diabetes	Not reported		0.0	(0.0 – 0.4)
Administrative	0.6	(0.0 – 1.3)	0.6	(0.0 – 1.5)
Research	0.0	(0.0 – 0.6)	0.2	(0.0 – 2.0)
Other	0.0	(0.0 – 1.1)	0.2	(0.0 – 1.0)

* A median of zero means that half or more of participating services reported not having any available staff within the respective staff group (they may have had vacant posts in these staff groups)

** The range shows the lowest and highest staffing level seen among participating centres for each staff group (as WTE per 75 patients); 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 characteristics or complexity, nor external/other factors that can impact on required staffing levels

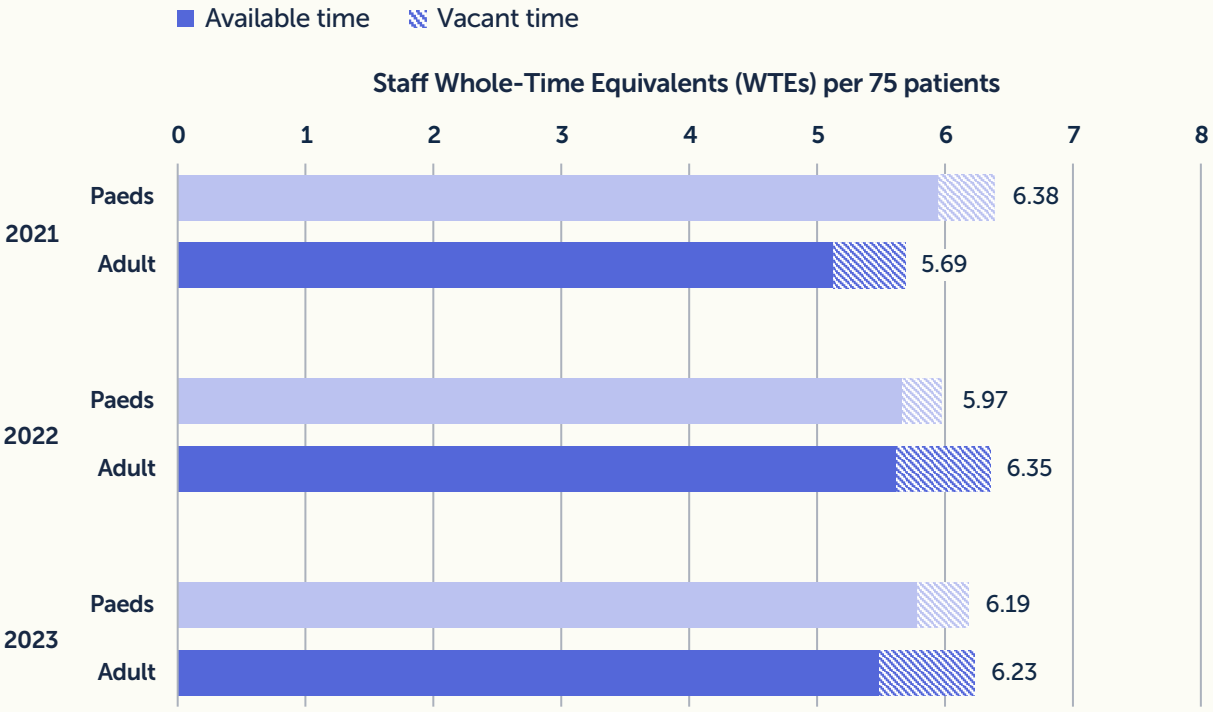
14 Cystic Fibrosis Trust, Standards for the Clinical Care of Children and Adults with cystic fibrosis in the UK. 2nd edition; 2011, last update 2022: **www.cysticfibrosis.org.uk/the-work-we-do/resources-for-cf-professionals/consensus-documents**

Insight: In October 2023, median staffing levels were similar when comparing paediatric and adult CF centres in most staff groups; however, several CF centres reported gaps in certain staff groups, and there was a lot of variation in staffing levels and availability between individual centres.

The different amounts of staff time available across participating centres (see ranges in Table 5) show that there appears to be variation in staffing levels between services. 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.

Figure 3: Overall staff time in October 2021, 2022 and 2023

NB: Average staff time was calculated based on all posts (incl. vacant and covered posts) and total population in 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)



Overall staff time for paediatric and adult populations served by participating CF centres was relatively similar year-on-year (6-6.4 WTE per 75 patients for paediatric and 5.7-6.4 WTE per 75 patients for adult centres). 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 had a higher proportion of vacant staff time year-on-year compared to paediatric centres.

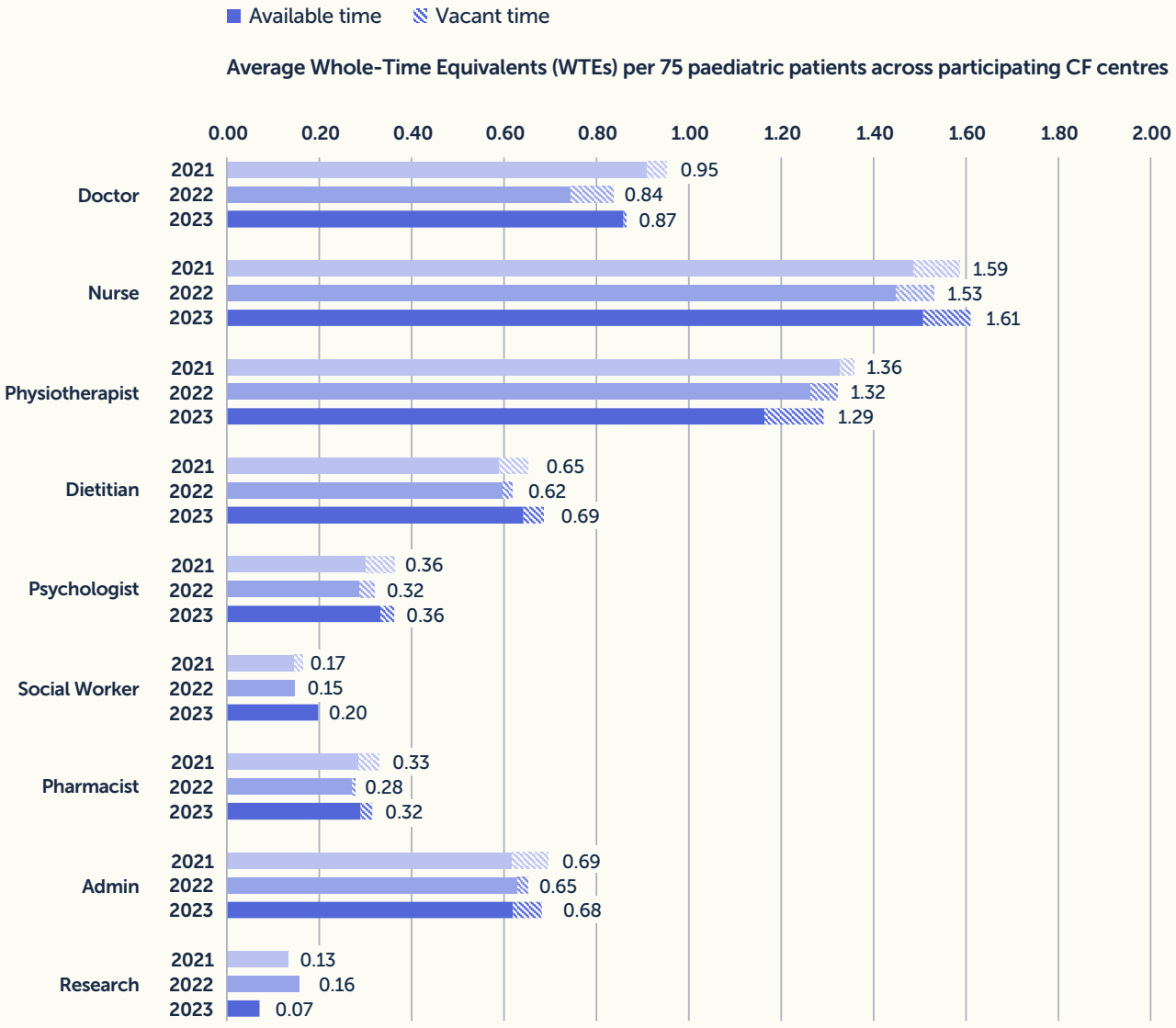
Insight: Overall staff time available to the CF population across participating centres fluctuates, and it will be vital to keep monitoring this in future.

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 specialties, Figures 4 and 5 provide a breakdown of WTE per 75 patients by staff group for both populations.

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

NB: Average staff time was calculated based on all posts in a staff group (incl. vacant/covered posts) and total population in the sample (with shared care patients attributed proportionately), where a vacant post was covered at different hours 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)



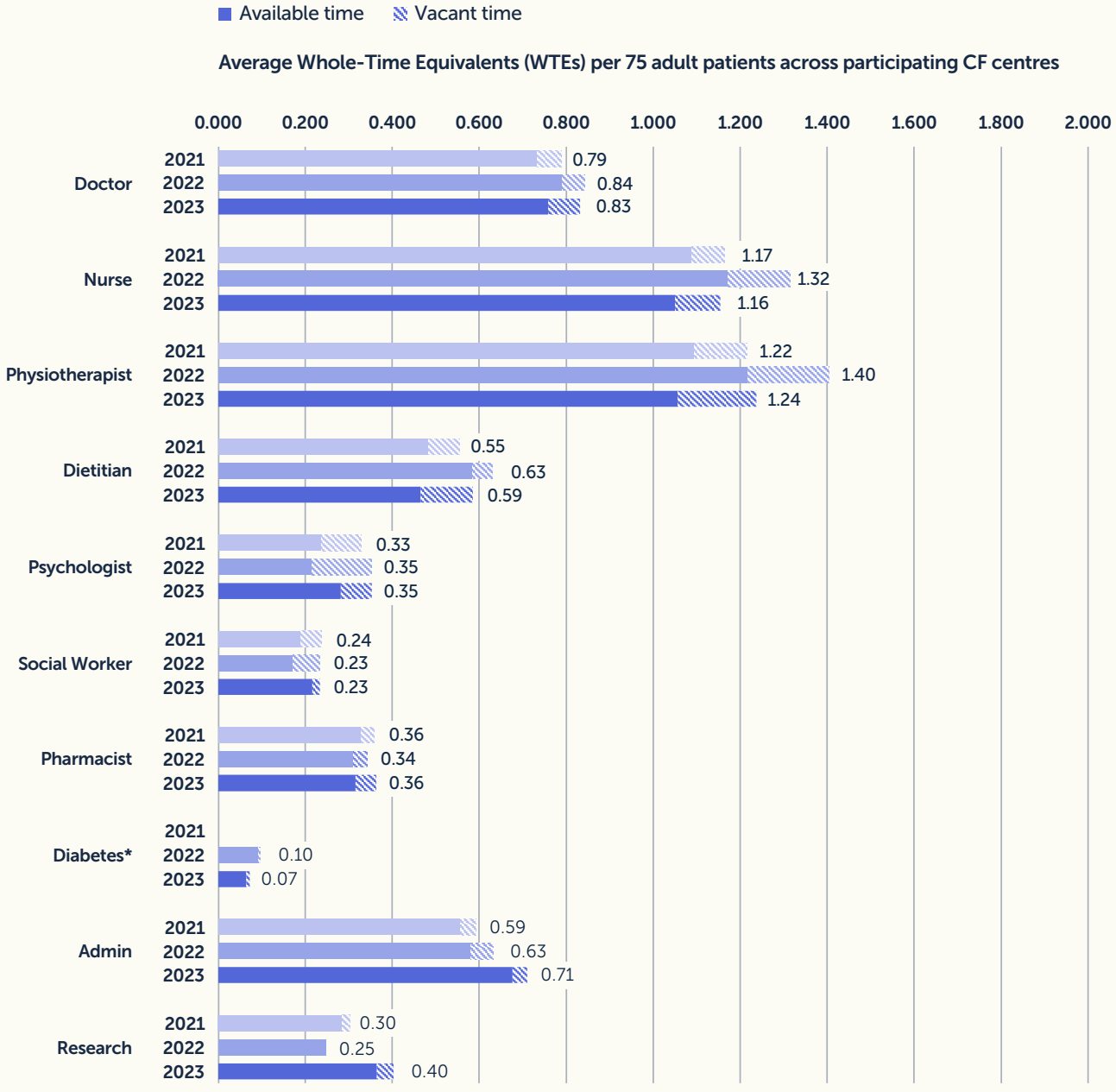
Average WTEs per 75 paediatric patients in our sample fluctuate within a range of approximately 0.05-0.1 WTEs per 75 patients for most staff groups (Figure 4). Between 2020 and 2022, average staff time across the paediatric population served by services participating in the staffing tool appeared to have reduced slightly year-on-year[15], which is not a trend that has continued in the October 2023 data. The apparent reduction over time between 2020 and 2022 may have been impacted by differences in our sample, and/or there may have been a slight improvement in staff availability in 2023 compared to 2022, although median staff time in the 2023 sample was comparable to previous year's samples.

15 Cystic Fibrosis Trust, UK CF Service Resourcing 2020-2022, published March 2023

Nurses and physiotherapists were consistently the staff groups with the most time available per 75 patients in paediatric and adult services, followed by medical and dietetics staff, with well below 0.5WTE per 75 patients available from psychology, social work and pharmacy (Figures 4 and 5).

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

NB: Average staff time was calculated based on all posts in a staff group (incl. vacant/covered posts) and total population in sample; 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)



*Diabetes staff were included as a separate group since 2022

Average WTEs per 75 adult patients in our sample fluctuate within a range of approximately 0.02-0.15 WTEs per 75 patients for most staff groups (Figure 5). For nurses and physiotherapists, fluctuations were larger, particularly in 2022, which was likely due to a smaller number of adult services taking part that year, impacting the results. Similar to findings from paediatric centres, average WTEs available for adult CF psychology, social work and pharmacy were consistently lower than for the top four staff groups shown.

Diabetes staff were included in the staffing tool for the first time in October 2022, when eight of 18 adult CF centres (44.4%) reported having diabetes staff in their CF MDT. In October 2023, a similar proportion (10 of 23; 43.5%) declared diabetes staff in their CF MDT. The overall WTEs available per 75 patients across our full sample are, therefore, relatively low (0.07), and as with psychosocial staff groups, it is important to reiterate that not all centres had diabetes staff available (Table 3).

Insight: Average staff time from most specialties was relatively similar between paediatric and adult populations, but slightly more nursing time was available in paediatrics.

When looking at average staff time, it is important to consider context. In October 2021, the COVID pandemic might have been impacting staffing levels in CF services in various ways, for example, with existing staff being drafted in to support the pandemic response. Furthermore, 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 in roles and/or WTEs within CF services to match changes in patient numbers.

Further cycles of the staffing tool will help monitor staff time available and how this changes over time, including in light of ongoing NHS-wide workforce challenges. Other factors that may impact staffing levels include changing patient needs due to more widespread use of modulator drugs, as well as the digitalisation of the NHS and increased use of remote monitoring and virtual care.

2.1 Staff seniority

Staffing levels vary not only by the types of roles and overall staff time available but also by the seniority of such roles. 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 continue to report larger proportions of roles at Band 5 or below, this difference was not as pronounced in later years. In October 2023, 18.5% of roles in adult care were Band 5 or below, compared to 14.5% in paediatric care, similar to what was observed in 2021 and 2022.

Figures 6 to 15 show staff time available across children and adults with CF under the care of participating services in October 2023 (as WTEs per 75 patients). The paediatric and adult 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 proportionally attributed. As such, the sample populations include patients from centres that did not have all staff groups in their MDT, which will result in low availability for certain staff groups when looking at staff time across the full sample population. Therefore, staffing levels shown in Figures 6 to 15 should not be interpreted as recommended staffing levels in any way.

Staff time figures are presented for each staff group separately and split by seniority (NHS Agenda for Change banding / medical grading)[16]. 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. Average values have been rounded to two decimals in all figures below unless the value for a band was below 0.005 WTE.

16 NHS England, Agenda for Change; 2022: **Agenda for change - pay rates | Health Careers**

Figure 6: CF Medical staff time available per 75 patients by banding Oct23

NB: Based on 0.86 (paeds) and 0.76 (adult) WTE per 75 patients medical staff time

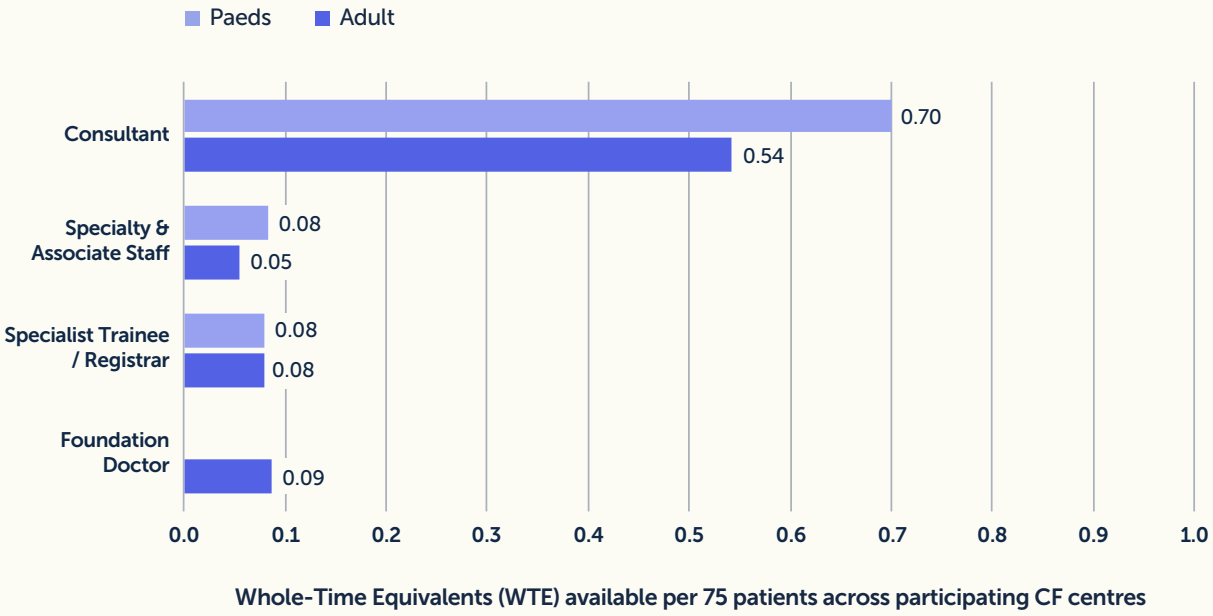


Figure 7: CF Nursing staff time available per 75 patients by banding Oct23

NB: Based on 1.51 (paeds) and 1.05 (adult) WTE per 75 patients nursing staff time

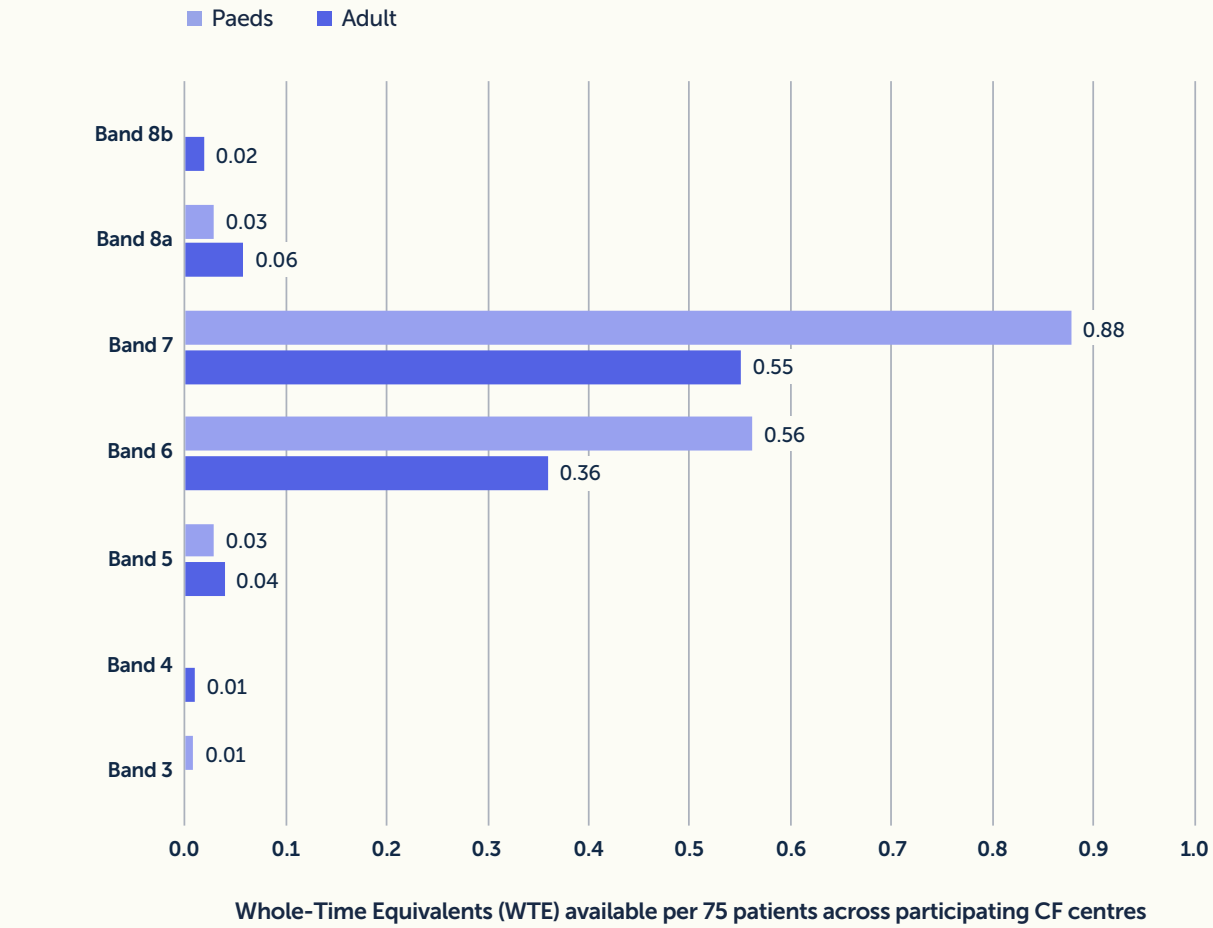
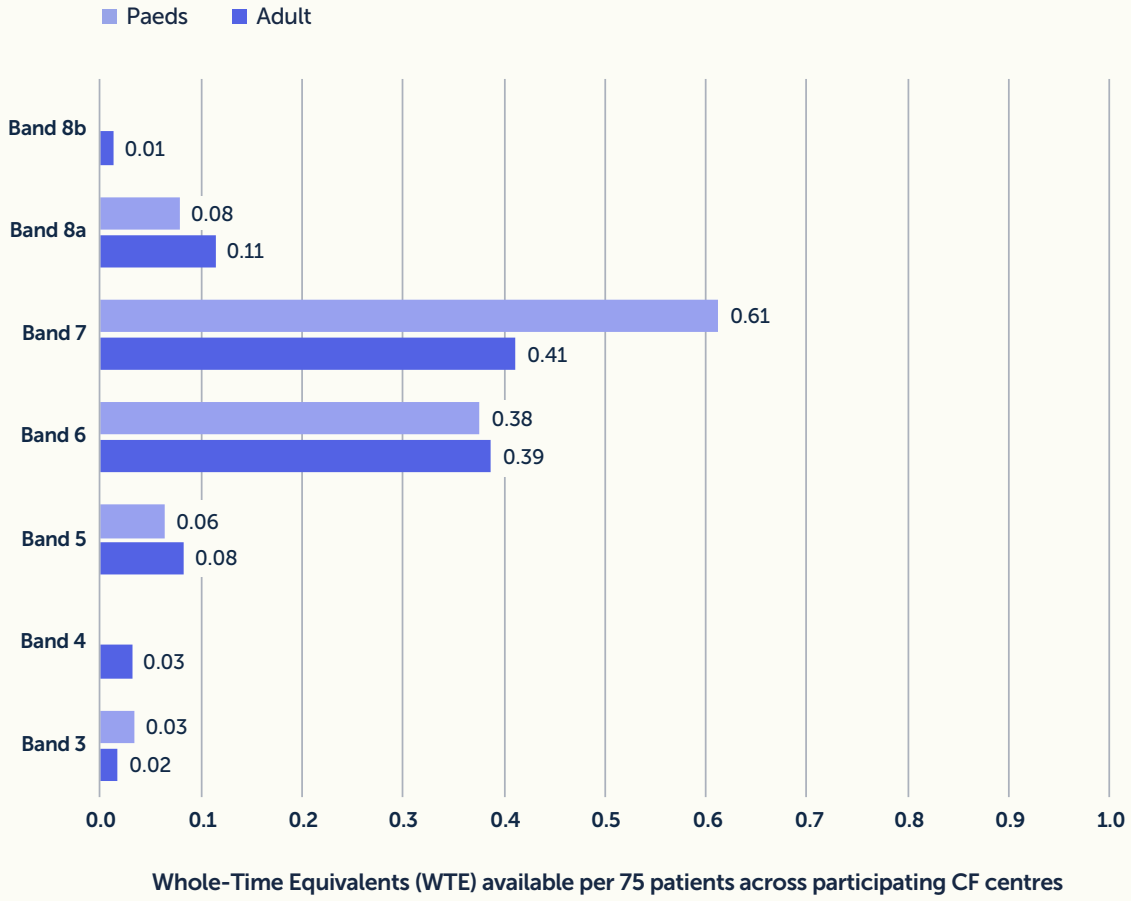


Figure 8: CF Physio staff time available per 75 patients by banding Oct23

NB: Based on 1.16 (paeds) and 1.06 (adult) WTE per 75 patients physio staff time



Specialist CF medical (Figure 6), nursing (Figure 7) and physiotherapy (Figure 8) staff were the three groups with the most staff time available overall. Banding for doctors differs from other NHS staff banding, with most medical staff in CF centres employed at consultant level (Figure 6). The most junior medical roles (Foundation Doctors) were only available in adult CF centres.

Similar to our findings in previous years, the majority of physiotherapists and nurses were employed at Bands 6 or 7. While overall time available from CF dietitians was lower, this staff group was also mainly employed at Bands 6 and 7 (Figure 9).

Figure 9: CF Dietetics staff time available per 75 patients by banding Oct23

NB: Based on 0.64 (paeds) and 0.46 (adult) WTE per 75 patients dietetics staff time
NB: One Band 3 post in paeds and one Band 4 post in adult care not shown

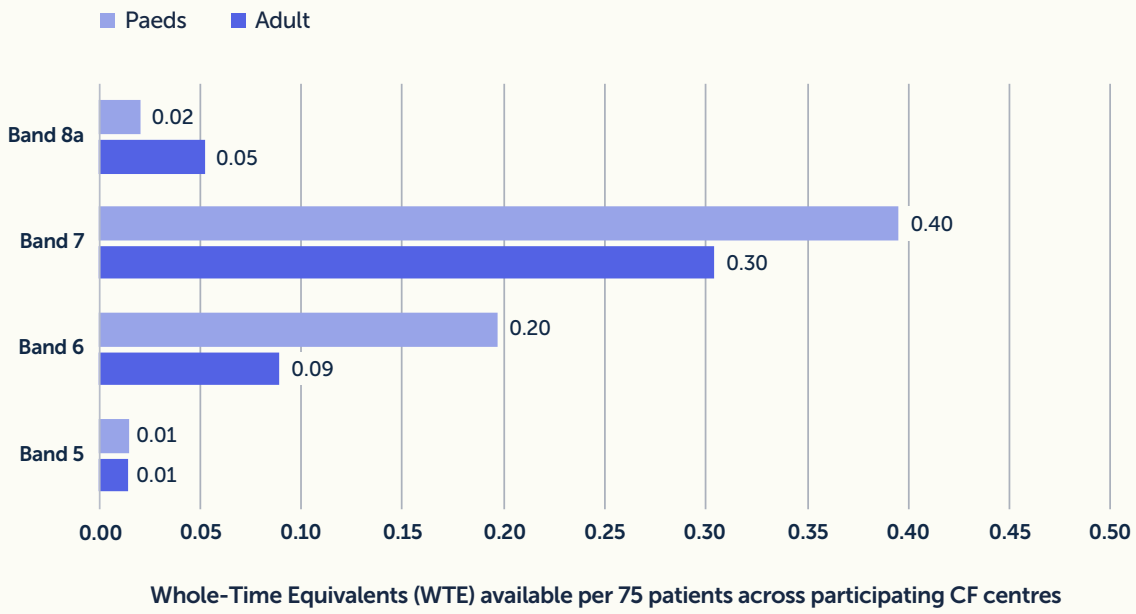


Figure 10: CF Psychology staff time available per 75 patients by banding Oct23

NB: Based on 0.33 (paeds) and 0.28 (adult) WTE per 75 patients psychology staff time

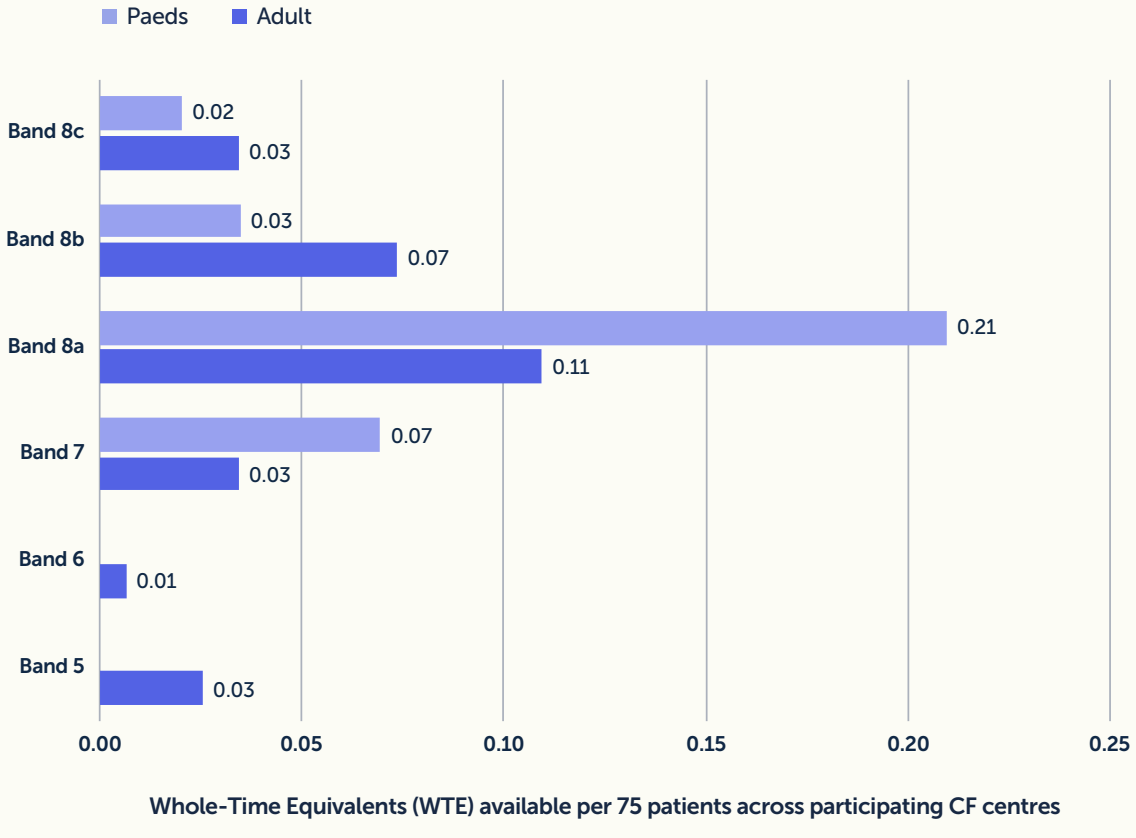
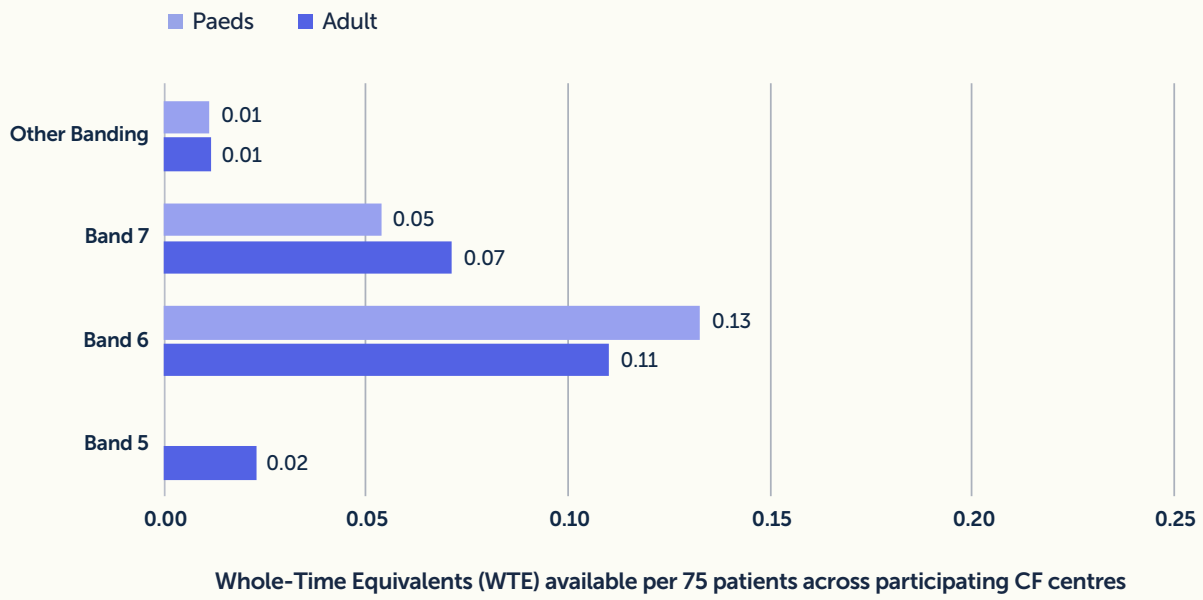


Figure 11: CF Social work staff time available per 75 patients by banding Oct23

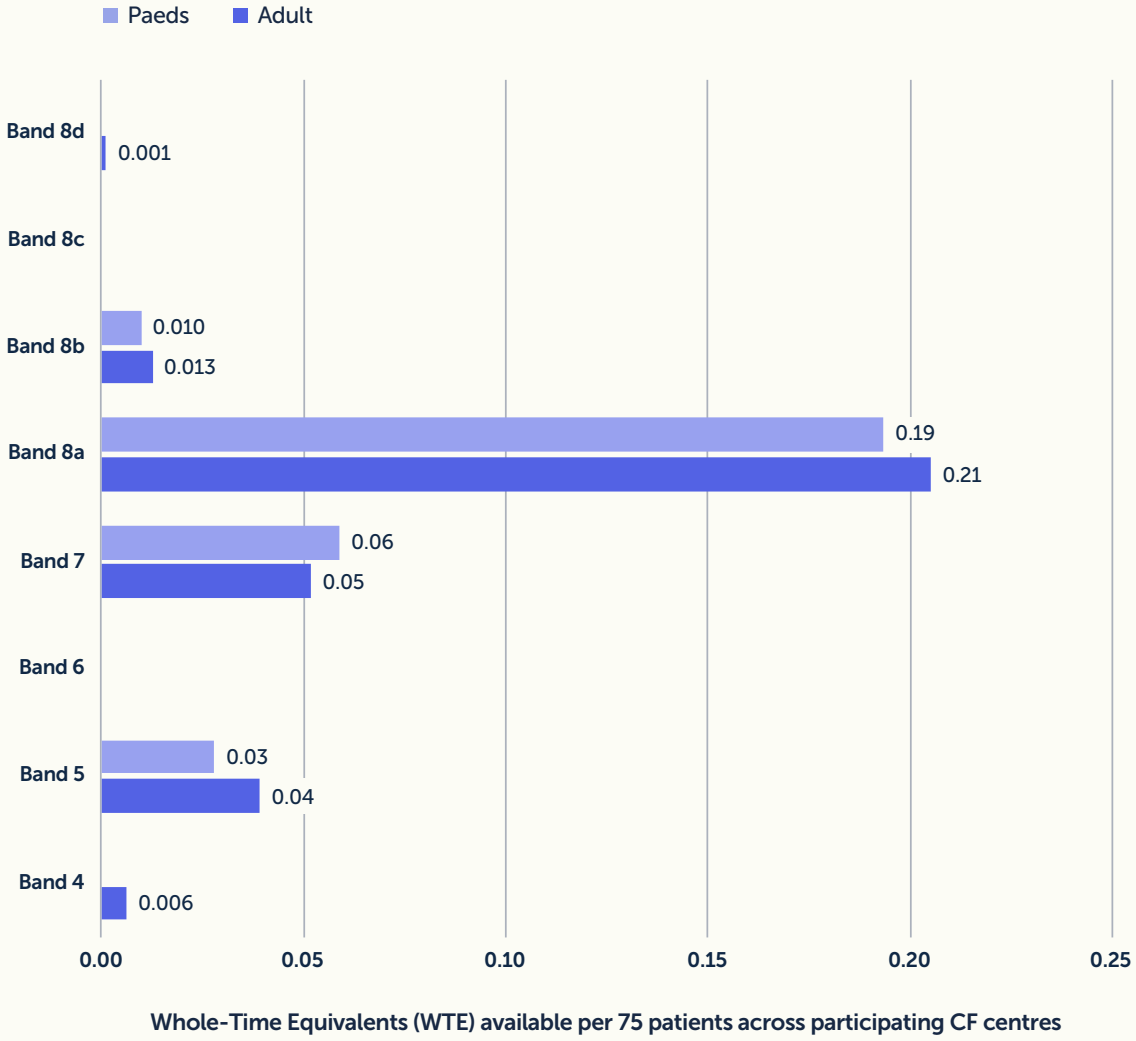
NB: Based on 0.20 (paeds) and 0.22 (adult) WTE per 75 patients social work staff time
NB: One Band 3 post in adult care not shown



For CF psychologists, social workers, and pharmacists, the banding distribution of staff was similar across paediatric and adult services. Psychology and pharmacy staff appeared to accumulate at higher bandings than other staff groups, with most employed at Band 8a (Figures 10 and 12). In contrast, most CF social workers were employed at Band 6 (Figure 11). It is important to note that this is based on WTEs available across the whole population cared for by participating centres, and not all services said that they had psychologists, social workers, or pharmacists in their CF MDT in October 2023 (Tables 2 and 3), which results in average WTE available to the population being much lower compared to other staff groups.

Figure 12: CF Pharmacy staff time available per 75 patients by banding Oct23

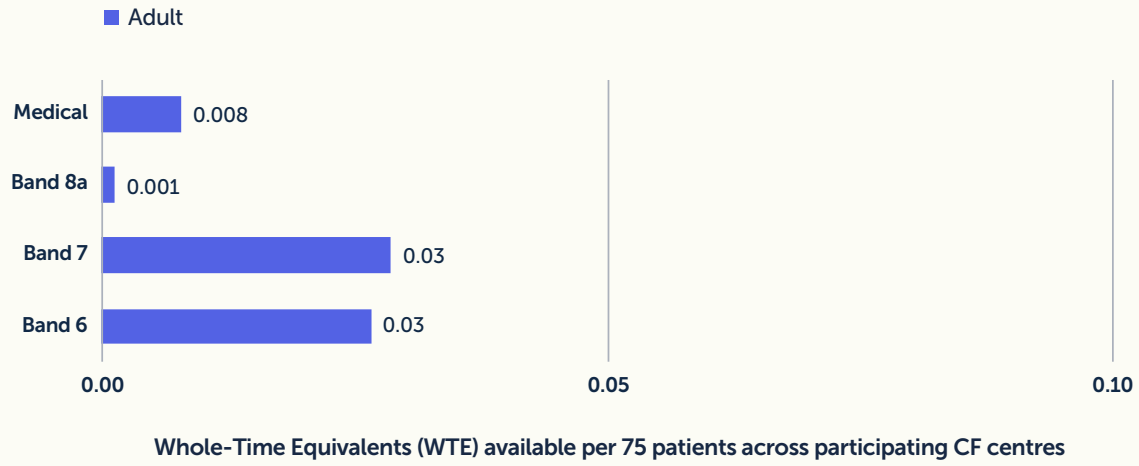
NB: Based on 0.29 (paeds) and 0.29 (adult) WTE per 75 patients pharmacy staff time



In addition to psychosocial and pharmacy staff, the staffing tool also asked about diabetes staff in CF MDTs within adult CF services. Figure 13 shows the average diabetes staff time available per 75 patients across the adult population in our sample. It is important to keep in mind that only 43% of adult services (n=10) said they had dedicated diabetes staff in their CF MDT, which is shown here. Other teams may have access to diabetes staff input funded through the specialist diabetes service or may refer to such services.

Figure 13: Diabetes staff time available per 75 adult patients by banding Oct22

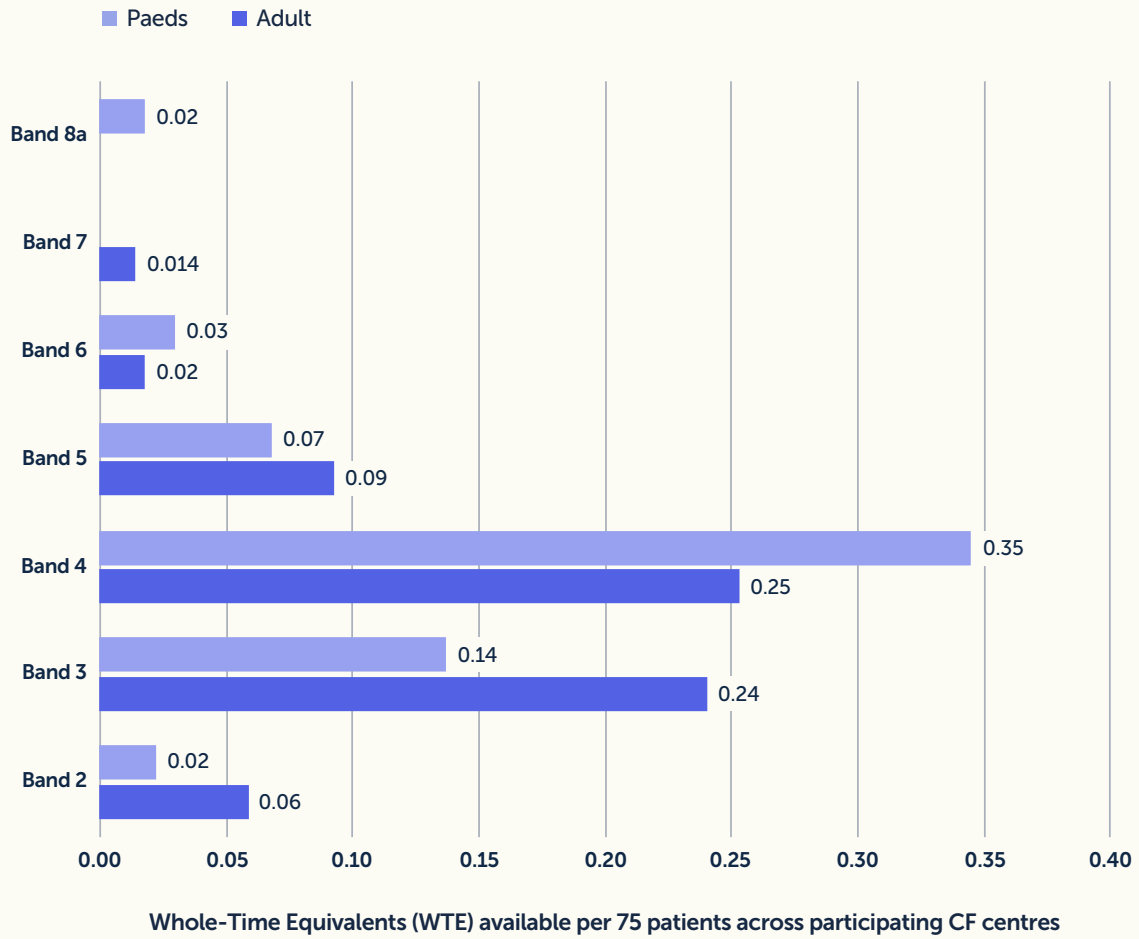
NB: Based on 0.06 (adult) WTE per 75 patients diabetes staff time



Administrative staff, such as secretaries and database coordinators, concentrated at Bands 3 and 4, with slightly more senior staff time at Bands 6 and 8a available for the paediatric population compared to adults.

Figure 14: Administrative staff time available per 75 patients by banding Oct22

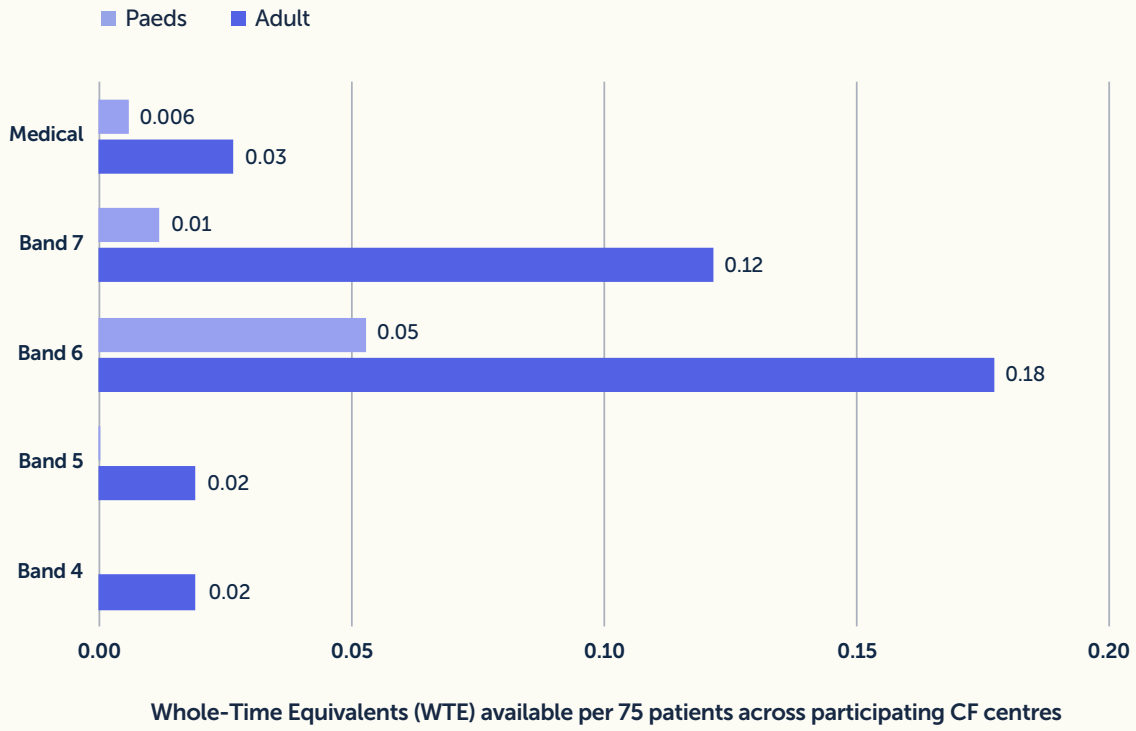
NB: Based on 0.62 (paeds) and 0.68 (adult) WTE per 75 patients administrative staff time



Most research staff within CF MDTs were employed at Bands 6 and 7. The adult population had more dedicated CF research staff time overall than was available to the paediatric population. However, fewer than half of participating CF centres in our sample in 2023 (20 of 46) said they had dedicated roles for research staff within their CF MDTs that were funded through their CF budget.

Figure 15: Research staff time available per 75 patients by banding Oct22

NB: Based on 0.07 (paeds) and 0.37 (adult) WTE per 75 patients research staff time



Research staff can ensure that clinical trial opportunities are presented in a timely way to people living with CF, which may result in improved access to the latest therapies.[17] It is important to note that, even where services did not report access to dedicated CF research staff within their MDT, they may be able to access other research staff within their NHS Trust, which would not be captured by the CF staffing tool.

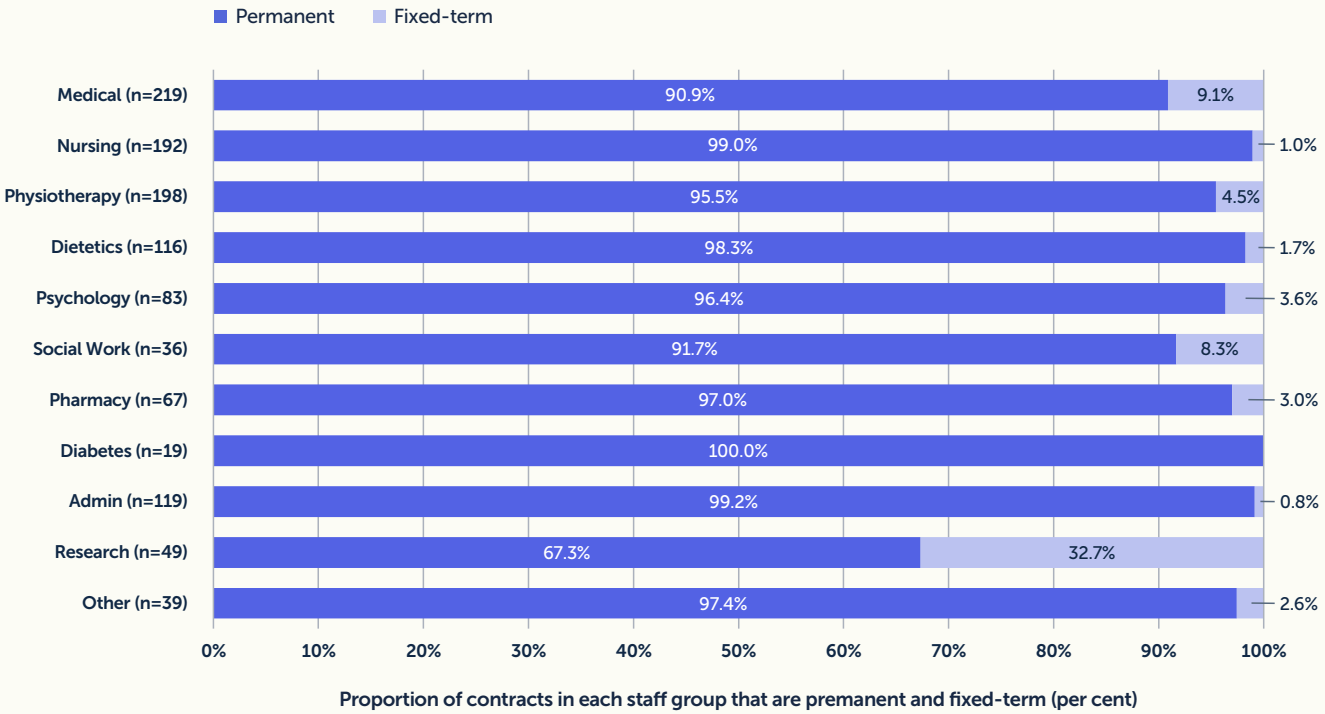
17 Cystic Fibrosis Trust, 2024: **Clinical Trials Accelerator Platform (cysticfibrosis.org.uk)**

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 fixed term ends. The proportion of FTCs in October 2023 was 5.2%, while 94.8% of roles had permanent contracts. While five per cent of staff on FTCs might not seem like much, it means 1 in 20 roles in CF MDTs were only fixed term.

Figure 16: Contract types by staff group in October 2022

NB: Based on 1,137 roles in participating paeds and adult centres, regardless of hours worked



For all staff groups except research staff, over 90% of contracts in place across participating CF centres were permanent, with 0-9.1% of contracts being fixed term, depending on staff group. 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 fixed-term contracts in CF MDTs (32.7%).

Section 3
Vacancies

Even when a centre has active staff in each group, it may not be fully staffed. As was the case in previous years, this is exemplified by physiotherapist vacancies in the latest dataset, where 22 vacancies were reported across our sample despite all participating centres reporting access to physiotherapists. Hence, it is important to consider the impact of vacancies, particularly long-term vacancies, on CF care delivery.

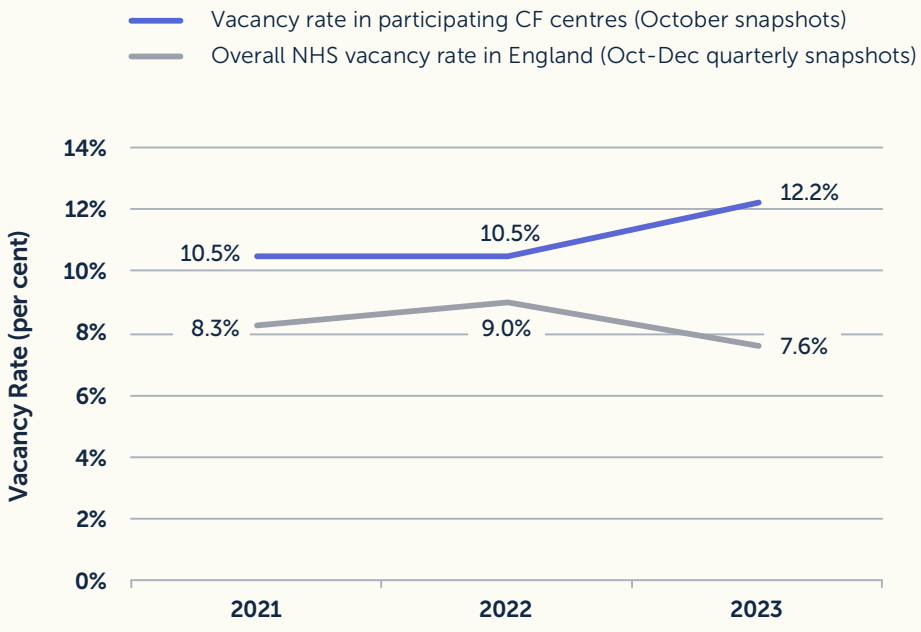
In October 2023, there were 133 vacancies across the 46 participating CF centres, with 17 of 23 paediatric and 20 of 23 adult centres reporting at least one vacancy. To better understand how vacancy rates in CF services compare with the NHS overall, the staffing tool collects information on currently active staff in each service, as well as vacant roles and cover arrangements, in the form of Whole Time Equivalents (WTE). Table 6 shows the vacancy rates across participating services over the last three years of the staffing tool. Our approach to calculate the vacancy rate is aligned with NHS Digital's approach to calculating the overall NHS vacancy rate and, therefore, does not indicate how much of the reported substantive gap is covered by temporary staff. However, Table 6 shows the vacancy rate as well as the time covered.

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

	2021	2022	2023
Planned CF Workforce (WTE)	688.54	571.27	706.68
Vacancies (WTE, incl. covered time)	72.06	59.78	86.47
Vacancy Rate* (%)	**10.47%**	**10.46%**	**12.24%**
Covered Arrangements (WTE)	11.53	10.13	14.25

*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 ÷ Planned WTE) x 100]

Figure 17: Vacancy rate changes over time, 2021-2023



In the last quarter of 2023 (October to December), NHS Digital's Vacancy Statistics[18] showed a vacancy rate of 7.6% across NHS providers in England, compared to a vacancy rate of 12.2% in participating CF centres in October 2023, 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 2023, the vacancy rate in participating CF centres was higher than the NHS vacancy rate overall at 12.2% versus 7.6%.

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

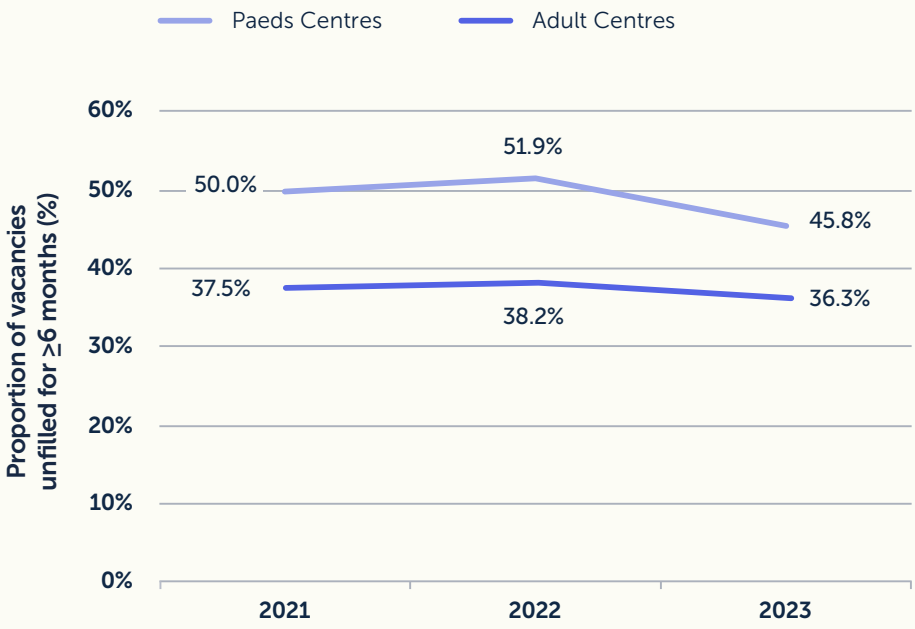
	Paeds Services (n=23)			Adult Services (n=23)		
	Proportion vacant over six months	**Vacant over six months**	**Total vacant posts**	**Proportion vacant over six months**	**Vacant over six months**	**Total vacant posts**
Medical (Doctors)	100%	1	1	27.3%	3	11
Nursing	40.0%	2	5	21.4%	3	14
Physiotherapy	28.6%	2	7	46.7%	7	15
Dietetics	0%	0	1	33.3%	4	12
Psychology	100%	3	3	50.0%	5	10
Social Work	--	0	0	100%	2	2
Pharmacy	66.7%	2	3	0%	0	3
Diabetes	--	0	0	50.0%	1	2
Administrative	0%	0	3	75.0%	3	4
Research	--	0	0	--	0	3
Other	100%	1	1	25.0%	1	4
Total proportion of vacancies unfilled for more than 6 months	**45.8%**	**11**	**24**	**36.3%**	**29**	**80**

* Vacancies that are being covered are excluded from the total vacant count in Table 6; further information about cover arrangements is shown in Table 7

Adult CF services had more vacancies than paediatric services overall. Across participating paediatric and adult CF centres, more than half the vacant posts for psychologists (8 of 13, 61.5%) in CF MDTs had been unfilled for six months or more by October 2023. A higher proportion of vacancies in participating children's services remained unfilled for more than six months (46%) compared to adult services (36%). This finding was consistent with previous years and may indicate that paediatric services struggle to fill vacancies, which may be due to a number of reasons, such as the highly specialised nature of roles or financial pressures.

18 NHS Digital, NHS Vacancy Statistics England [Experimental Statistics: April 2015 – December 2023 – Tables]; March 2024: **NHS Vacancy Statistics (and previous NHS Vacancies Survey) - NHS Digital**

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

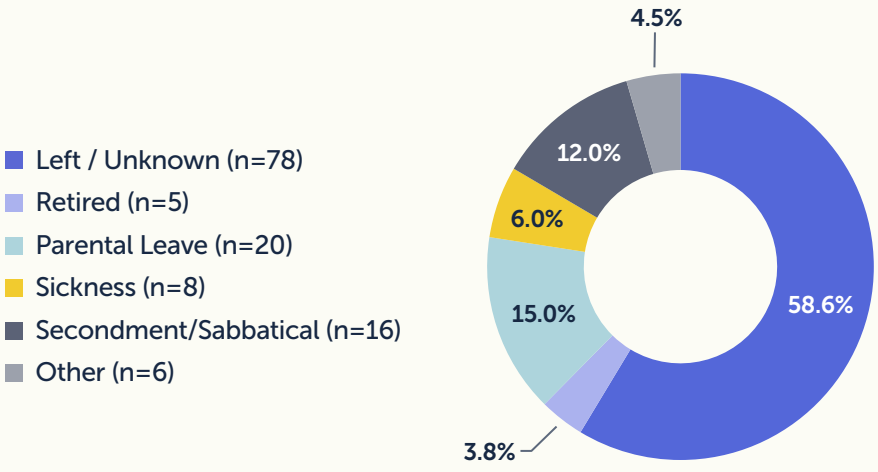


Insight: A higher proportion of vacancies in CF centres for children remained unfilled for six months or longer, while centres for adults reported a higher number of vacancies.

3.1 Vacancy reasons

Posts may be vacant for a number of different reasons, for example, due to staff moving on or retiring, or due to existing staff being on longer-term leave.

Figure 19: Vacancy reasons provided in 2023



Most posts were vacant due to staff having left or retired (62%), but 1 in 3 (33%) were vacant due to a contracted member of staff on parental or sick leave or on secondment. Six roles were reported vacant for other reasons, for example, due to the role being newly created.

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 133 vacant posts in October 2022, 29 were covered (21.8%); of these, only 14 (48.3%) were covered at the same or higher WTE level/banding than the vacant, substantive post.

Table 8: Vacancy cover arrangements

	Paeds 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**
2021	2	6	33.3%	7	13	53.8%
2022	10	12	83.3%	3	4	75.0%
2023	5	13	38.5%	9	16	56.3%

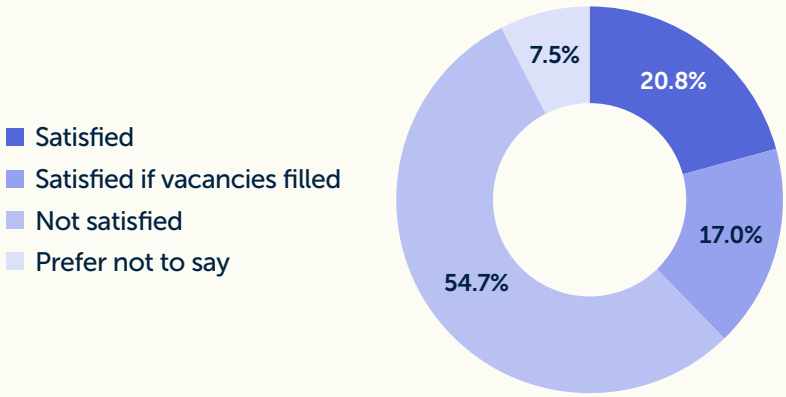
In October 2022, services appeared to have relatively good proportions of vacancies that were covered at the same level or higher in terms of staff banding and WTE. However, in October 2023, the data show that fewer than half the covered posts are covered at the same level, which is similar to findings in 2020 and 2021.

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 2023

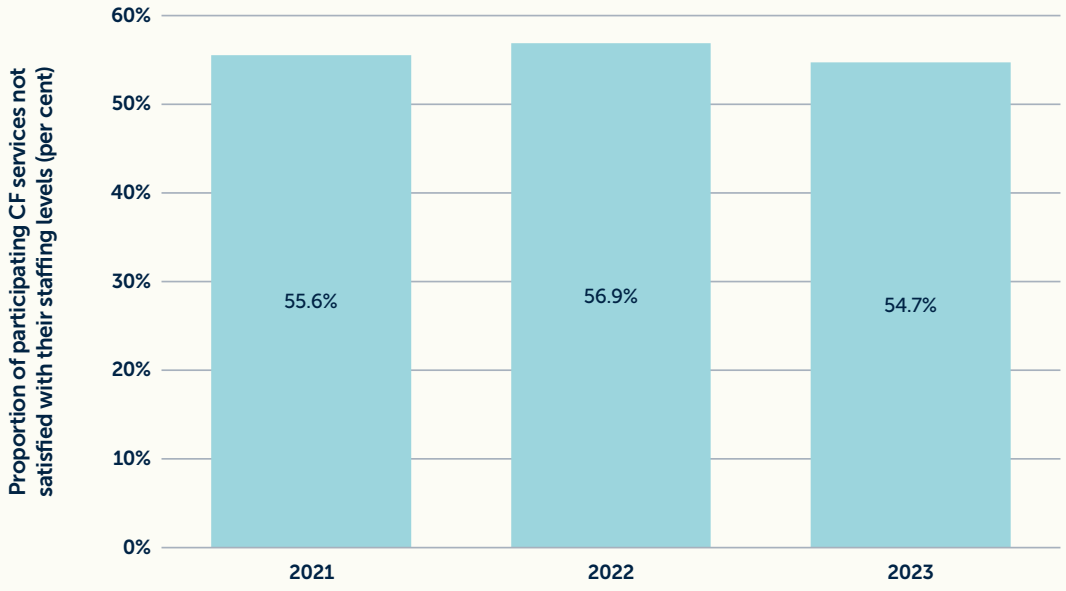
NB: Responses from clinics were counted individually in this calculation; total responses included: 52; 46 CF centres and 7 associated network clinics



In October 2023, only 11 responding services (20.8%) said they were satisfied with their staffing levels, while nine (17.0%) confirmed they would be satisfied if their existing vacancies were filled. Similar to previous years, more than half the services (54.7%, n=29) said that they were not satisfied with their staffing (Figure 21).

Figure 21: Proportion not satisfied with staffing levels each year, 2021-23

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



Insight: More than half of participating CF services said they were dissatisfied with their staffing levels.

Each year, fewer than half of participating CF services reported that they were satisfied with their staffing levels. 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. However, a new response category was included in October 2023 to explore if services would be satisfied with their staffing if all their vacant roles were filled. Interestingly, only a small number of services selected this new option, indicating that staffing challenges reported by CF teams go beyond issues with vacant roles and that a lack of provision for roles 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. Satisfaction levels followed comparable patterns in paediatric and adult services, with satisfaction higher in 2020 and then declining (Figures 22 and 23).

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

NB: 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.

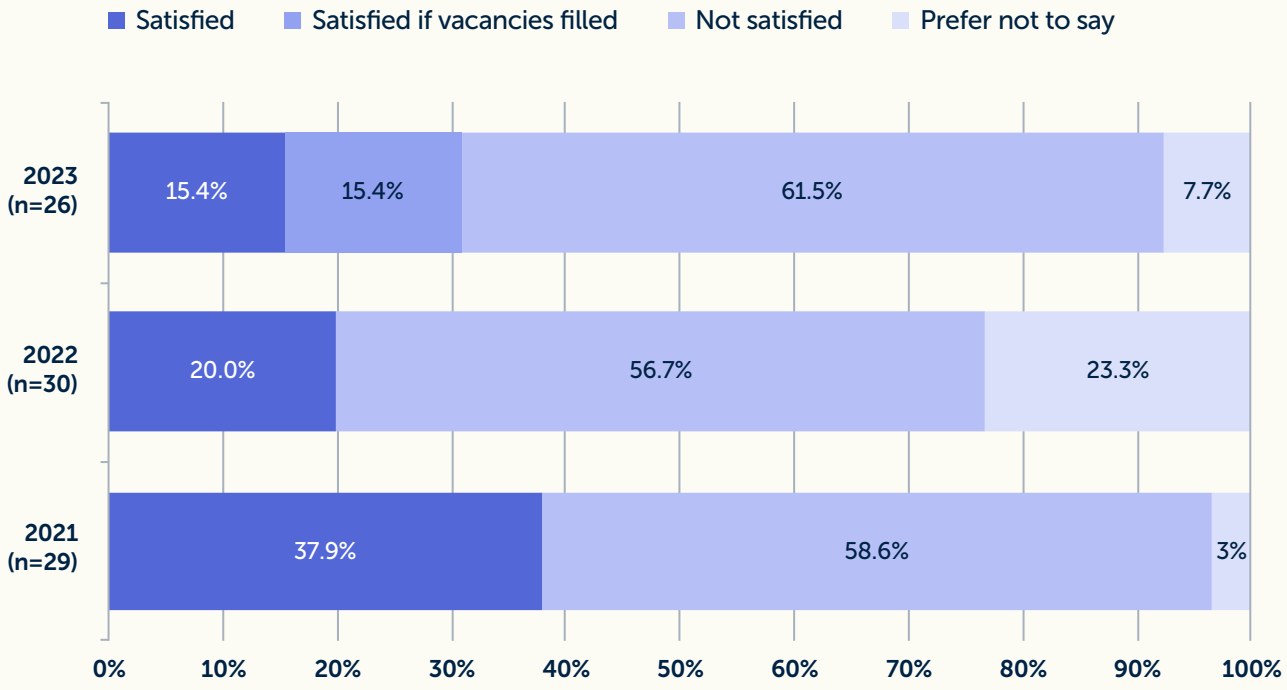
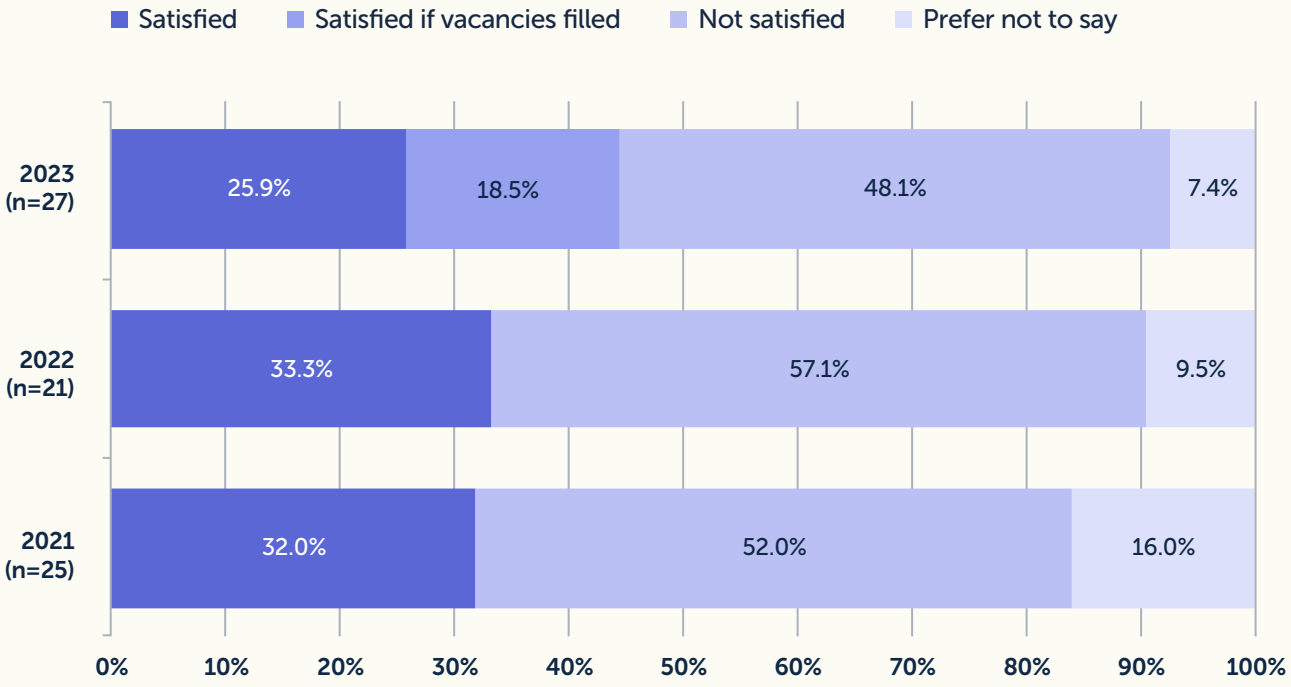


Figure 23: Satisfaction with staffing levels in adult services over time

NB: 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.

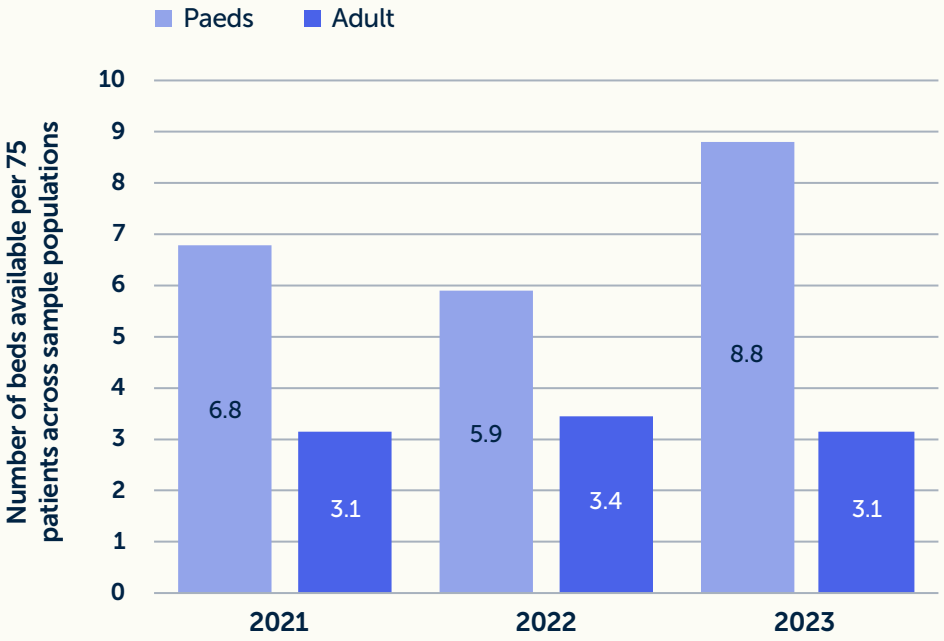


Section 5
Facilities

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 Care[19] recommend that people with CF should not share bathrooms with others during inpatient stays. The staffing tool collects data about bed availability, specifically, the number of beds teams have access to for their CF patients, as well as the proportion of these that are in en-suite rooms.

Figure 24: Bed availability across sample populations 2021-2023

NB: Bed availability shown as beds available per 75 patients in our sample populations (paediatric and adult), with shared care patients included

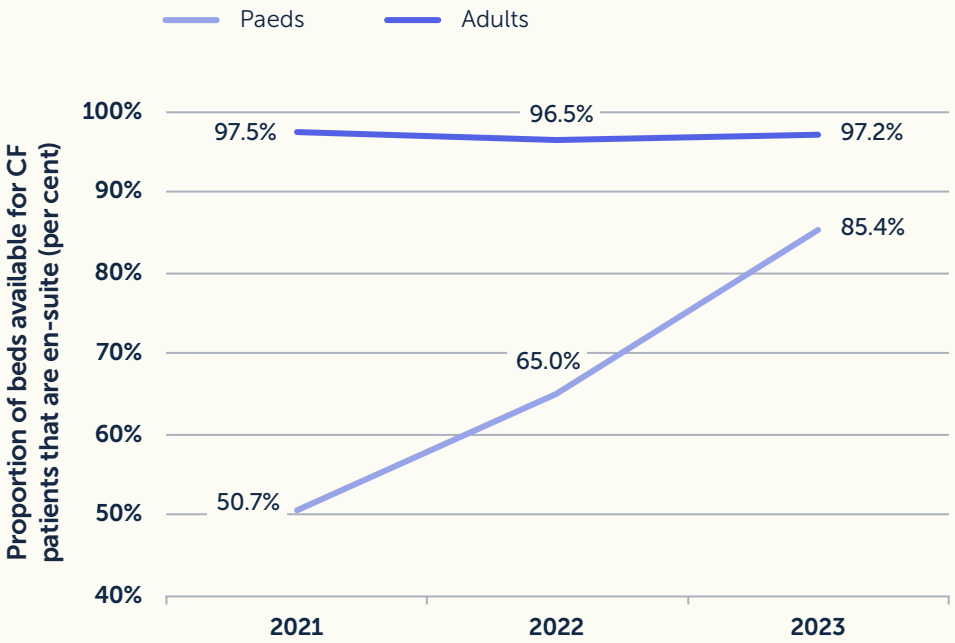


Year-on-year, the number of beds available per 75 paediatric patients was higher than for the adult population, where bed availability remained relatively stable over the years (Figure 24). However, beds in paediatric services were less likely to be en-suite, though en-suite availability has increased over time (Figure 25).

19 Cystic Fibrosis Trust, Standards for the Clinical Care of Children and Adults with cystic fibrosis in the UK. 2nd edition; 2011, last update 2022: **www.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

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



In October 2021, just 50.7% of beds available in paediatric services that participated in the staffing tool were en-suite, but this rose to 85.4% in 2023. 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.

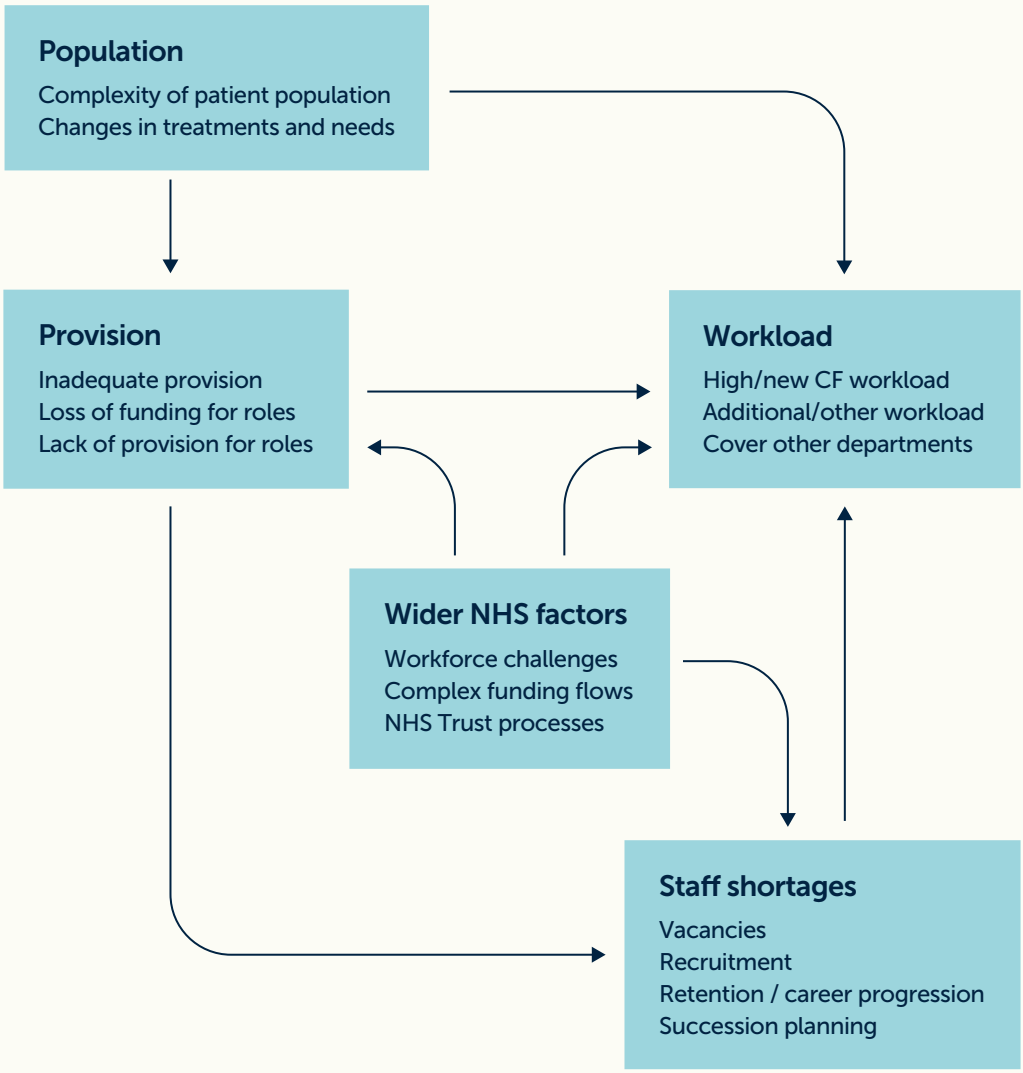
Section 6
Challenges and innovations

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

In October 2023, participating CF centres and some of their network clinics shared details about 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 (i.e. whether or not it was satisfied) in Oct 23.

Figure 24: Factors driving staffing challenges within CF teams



As with previous years, two staffing challenges frequently highlighted by participating services were vacancies and issues with recruitment to vacant roles, resulting in shortages and increasing pressure on existing staff and services.

> "Two vacancies with a further two nurses leaving soon. Reduced ability to support across all clinics, potential reduction in IV capacity, day case reviews, impact on staff morale and well-being." **Adult service (Dissatisfied)**
>
> "We haven't been able to recruit in psychology, so a backlog has occurred, thus not being able to provide sufficient help to patients. Nurses have been signposting to online resources when needed." **Paediatric service (Dissatisfied)**
>
> "Sickness and absence - short and long term - is a problem, along with vacancies that do not fill first round of advertising." **Adult service (Satisfied if vacancies filled)**
>
> "Difficulties with delays in recruitment - posts are not quickly approved and [this] results in delays in advertisement going out, which means there is often a gap between posts." **Paediatric service (Satisfied if vacancies filled)**

As discussed in **Section 3 (Vacancies)**, the vacancy rate in CF services was slightly higher than the overall rate in the NHS in the final quarter of 2023. There were 133 vacancies in participating CF services, many of which had remained unfilled for six months or more. In addition, only a small proportion of vacancies had cover arrangements in place. It is, therefore, unsurprising that services discussed vacancies and recruitment as significant challenges they were facing.

Aside from vacancies for existing roles, provision for roles in the CF MDT was also raised as a challenge, both in terms of inadequate provision and a loss or lack of provision for certain roles. This was particularly, but not exclusively, highlighted for CF pharmacists, psychologists and social workers, for whom workload was also often perceived to have increased.

> "We are insufficiently staffed in pharmacy, as there has not been an uplift in staffing numbers despite a significant rise in patient numbers for many years. As a consequence, not all patients are reviewed by the pharmacy team at annual review consultation." **Adult service (Dissatisfied)**
>
> "Pharmacy isn't enough hours to deal with patients and workload - nurses organising modulator prescriptions along with weight and bloods to be able to prescribe. No social worker - again nurses filling that void." **Paediatric service (Dissatisfied)**
>
> "We have no social worker. We do not have a replacement for retired colleague. Now this is no longer out to recruitment, as advertised jobs we had have been filled by non-CF colleagues." **Paediatric service (Dissatisfied)**
>
> "There are restrictions with Psychology as it is only telephone contact at present." **Paediatric service (Satisfied if vacancies filled)**
>
> "The CF psychology service is overstretched, with increasing demand for this service." **Adult service (Satisfied)**
>
> "We have no local dietitian - this is a huge risk locally - the service was withdrawn." **Adult service (Dissatisfied)**

Unsurprisingly, with limited provision and workforce shortages not only in CF services but across the wider NHS, another common challenge shared by services focused on workload for existing staff. Several services reported staff taking on additional non-CF workload and covering for other departments or specialties. Several also mentioned the increasing and new workload generated by new therapies and processes in CF care.

> "Pressures on CF staff time have been increased in the last year in terms of professional responsibilities such as supervision of non-CF staff, service development/professional activities outside of CF. Medical staffing PAs are largely not being realised due to respiratory pressures." **Adult service (Dissatisfied)**
>
> "The majority of our team cover respiratory service as well as CF, so the amount and complexity of the respiratory patients can impact the time left for CF. New therapies, evidence-based practice and IT systems all take longer to complete and staffing is not adjusted to reflect this extra workload." **Paediatric service (Dissatisfied)**
>
> "Recruitment and retention of staff is very difficult, with resultant high turnover and lack of continuity. There is a lack of cross cover for maternity leave and long-term sick leave. However, CF MDT often cover other departments." **Adult service (Satisfied if vacancies filled)**

While many challenges experienced by CF services reflect challenges faced by services across the NHS, there are some important challenges either specific to or impacting more on CF care.

> "We could do with more psychology, social work & youth worker hours. This reflects the changing complexity of our patients post Kaftrio treatment." **Adult service (Satisfied)**
>
> "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)**

Insight: CF teams face staffing challenges, both as a result of ongoing staff shortages in the NHS as a whole, as well as novel treatments for CF that have led to increases in life expectancy and shifts in the care needs of the CF community.

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 expanding existing roles and seeking additional funding for new posts to working with technologies, other teams and community organisations to change the way care is delivered.

Figure 25: Staffing innovations and mitigations used by CF teams

Staff & team development

- Expanded and specialist roles
- Non-medical prescribers
- New and emerging roles
- Uplifting existing roles
- Teaching the next generation
- Network/shared care meetings
- Access to non-CF funded staff
- Collaborating beyond CF team

Specific programmes

- Joint transition clinics
- Dedicated adolescent clinics
- Commit to fit for teenagers
- Remote 'Bone Building Camp'
- Parental procedural anxiety
- Outreach work with schools
- Diabetes education clinic
- Sustainability education

Care delivery

- Virtual appointments (use of NHS Attend Anywhere)
- Virtual transition clinics
- Return to F2F care
- Community services and care:
  - Home monitoring
  - Home IVs
  - Virtual ward
- Improved/streamlined processes
- Increased clinic capacity
- MDT on-call system
- CFQR screening
- POC audiometry

Other activities

- Quality improvement meetings and projects
- Research and clinical trials
- National CF database (Scotland)

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 changes in roles and responsibilities of existing staff and changes to how care is delivered, though despite these innovations, staffing often remains a challenge.

Changes to the team, roles or responsibilities

Developing existing members of the CF MDT plays an important part in addressing staffing challenges. As we reported previously, many CF centres have non-medical prescribers working in their service, such as nurses, pharmacists and physiotherapist prescribers, or are training staff to become non-medical prescribers. Distributed prescribing responsibilities offer an effective way to reduce reliance on medical prescribers 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.

> "We have 3 CF nurse specialists who are non-medical prescribers within the team." **Paediatric service (Satisfied)**
>
> "We now have two pharmacist non medical prescribers (NMP) and one nurse has commenced the NMP course." **Adult service (Satisfied if vacancies filled)**
>
> "Non-medical prescribers are important to our delivery model. We have 3 nurses, 2 pharmacists and 2 physiotherapists who prescribe as well as our medical team." **Adult service (Dissatisfied)**

Apart from non-medical prescribing, existing CF service staff often also take on additional responsibilities to deliver the CF service. Advanced practice roles, for example, allow physiotherapists to take bloods and carry out port flushes. Some services have also implemented nurse-led clinics.

> "We have trained senior specialist nurse in being able to undertake medical examinations and prescribing - this has been extremely useful as she is able to see patients in clinic independently." **Adult service (Dissatisfied)**
>
> "[Three] members of the MDT doing an Advanced Care Practitioner Masters' degree (x2 CNSs and x1 physio)." **Adult service (Dissatisfied)**

Several participating services have also added new specialist roles into their CF teams to support the service, such as CF youth workers, occupational therapists, diabetes nurses and advanced practitioners.

> "New post as CF occupational therapist. We also have a diabetes consultant who does sessions in CFRD and musculoskeletal physiotherapists who do sessions in CF." **Adult service (Satisfied)**
>
> "We have started a Band 4 Dietetic Assistant Practitioner that supports us with routine virtual clinic appointments and screens clinic patients for the dietitian to minimise dietetic input needed and streamlines who really needs input from the dietitian. [They] also lead on upkeep of the HEF CF patient list for our hospital and update budget holders as required." **Adult service (Dissatisfied)**
>
> "Development of Band 4 Assistant practitioner for exercise provision and support across MDT." **Adult service (Dissatisfied)**
>
> "Temporary Band 5 Psychology Assistant will be out for advert soon as there are no Band 8a Psychologists to pick up the vacancy gaps across adult and paed services. The assistant will take on the role of referrals and CFQR." **Paediatric service (Dissatisfied)**

Some services in the staffing tool also shared that they are working on business cases to create new roles or uplift existing staff to address challenges, while others are actively involved in teaching to train the next generation of CF professionals.

Additionally, many CF services also work closely with other relevant specialties, such as Diabetes and Transplant teams, or even have other specialties feed into the CF MDT which are not funded from the CF budget.

> "Band 7 nurses providing teaching on the nursing degree. [We are] improving the CF Diabetes service: working more closely with the Endocrine/Diabetes Team; programmed treatment unit now doing OGTTs [Glucose Tolerance Tests]. Working closely with Radiology to increase the number of DEXA scans done annually." **Paediatric service (Dissatisfied)**
>
> "CF MDT staff not funded though CF budget in our department include GI consultant, Renal Consultant, Diabetic Consultant, Microbiologist, and Palliative care consultant." **Adult service (Dissatisfied)**

Changes to care delivery

Many CF services have adapted how care is delivered to meet the changing and diversifying needs of their patient population. Specific changes to care delivery in recent years include the continued use of remote monitoring technologies and virtual or telephone consultations, expanded homecare offers, and the introduction of new screening tests for patients.

As the pressures of the pandemic have eased, more CF care is now delivered face-to-face again, although many services continue to take a hybrid approach to delivering care, using technologies such as NHS Attend Anywhere. Some services acknowledged ongoing work to agree on the best model of care for the future, aligned with the changing needs of the community.

> "We have maintained some virtual communications particularly with schools and social services so external meetings are conducted this way, reducing the time taken for this, as there is no travel involved. [And] we offer virtual clinic appointments for transition clinics so older adolescents do not have to miss so much school during their exam years." **Paediatric service (Dissatisfied)**
>
> "[We are] seeing patients who are well less frequently face to face." **Adult service (Satisfied if vacancies filled)**
>
> "There is an ongoing service evaluation and feedback exercise to inform the best approach to follow up in the post-modulator and post-COVID era, e.g. query: frequency of appointments, face to face vs. telemedicine, etc." **Paediatric service (Dissatisfied)**
>
> "We are looking at patients' requirements and frequency of attending the CF clinic." **Adult service (Dissatisfied)**

As highlighted in previous years' reports, use of remote monitoring equipment, such as home spirometry, continues within CF services, with several also reporting expanded homecare offers, including home physio, home IVs and virtual wards.

> "We use home spirometry [and] mailing sputum/cough swab samples." **Paediatric service (Satisfied if vacancies filled)**
>
> "Increase in community service to include physio and nurse home visits once vacancies have been filled. The MDT are looking into setting up transition outreach clinics." **Adult service (Dissatisfied)**
>
> "Utilisation and availability of community-based services for IV antibiotic administration e.g. Virtual Ward and Rapid Response." **Adult service (Satisfied)**

Finally, a few other changes to care delivery were mentioned, including implementation of new tests/assessments, such as CF quality-of-life screening and point-of-care audiometry.

> "In absence of a psychologist, nursing staff complete the CFQR questionnaires to help highlight the need for patients to be referred to other services." **Adult service (Dissatisfied)**
>
> "Routine CFQR screening at annual review [and] Patient Health Questionnaire-4 to routine clinic psychology contacts." **Paediatric service (Satisfied if vacancies filled)**

Specific, targeted innovations and mitigations

Several participating services also shared about targeted interventions they have implemented for specific groups. As was the case in previous years, one area of innovation was the transition from children's to adult services. A few centres mentioned joint transition clinics, as well as dedicated clinics and programmes for young people with CF.

> "Work streams implemented for annual assessment, transition clinic, and plans for joint transplant clinic in the future." **Adult service (Satisfied if vacancies filled)**
>
> "Ongoing Commit to Fit exercise programme for teenagers. Joint project between Physio and Dietetics on bone density Bone Building Camp (remote)." **Paediatric service (Dissatisfied)**

Other examples of focused interventions include adult services now offering tailored education on topics such as diabetes and environmental sustainability.

> "We have created a new weekly virtual dietetic/diabetes education clinic." **Adult service (Satisfied)**
>
> "[We offer] education around inhalers and sustainability." **Adult service (Dissatisfied)**

Quality improvement and research

Several services in the staffing tool confirmed they are having quality improvement meetings to regularly review quality of care and develop local improvement projects. Some mentioned specific QI projects they had completed on topics such as newborn diagnosis and parental needle-anxiety.

> "We continue to streamline our CF service so that it works more efficiently for patients and families." **Paediatric service (Dissatisfied)**
>
> "Embedding of quality improvement with designated QI leads." **Adult service (Dissatisfied)**
>
> "Weekly QI meetings to review service/systems." **Adult service (Dissatisfied)**

In addition, many services are actively supporting research and clinical trials, although some do not have dedicated capacity for this.

> "Embedded Researcher Fellowship Dietitian working within CF team." **Paediatric service (Dissatisfied)**
>
> "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 46 of 60 CF centres contributing in 2023. Findings from our Patient-Reported Experience Measures[20] show that CF teams are still delivering high-quality care, but our staffing tool data clearly shows evidence that teams 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 has all the roles that are recommended in the Standards of Care available in their service. While the new standards have not yet been published, they are expected to put continued emphasis on the role of multi-disciplinary CF specialist teams to enable holistic, person-centred care, particularly in the context of a growing and ageing adult population with CF. In addition, the new standards are expected to offer flexibility and allow for continued innovation in staffing, including the implementation of new and emerging roles, such as Youth Workers, Exercise Therapists, and CF Practitioners.

Our findings show that CF MDTs currently do not have consistent access to input from psychosocial, pharmacy and research staff, and there is little resilience to cover staff absences even where such roles are in place. While existing or alternative staff may take on some of these responsibilities, such cover arrangements often cannot fully replace a dedicated CF specialist and are usually only temporary. The fact that many CF services say they are struggling to recruit and/or retain qualified CF specialist staff, particularly psychosocial staff and pharmacists, is also concerning, especially where posts remain vacant long-term.

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 relevant best practice guidelines and complementary intelligence, including data on patient experiences and outcomes, for example, from the UK CF Registry and the Cystic Fibrosis Trust patient-reported experience survey.

However, from the insights provided by the staffing tool in 2023 and previous years, we can make some general recommendations that apply across the UK:

- Sufficient resourcing of CF services continues to be critical to ensure staffing levels are adequate to cater for the evolving and diversifying needs of the population and to ensure all people with CF can access the right professional(s) at the right time [Note: a review of the Standards of Care and NHS England's service specification is underway and expected in 2024].
- Exploring issues around staff recruitment and retention at national level is important to avoid vacancies remaining unfilled for long periods of time, particularly where there appear to be common challenges with attracting suitably qualified staff, such as in psychology, social work and pharmacy.
- 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 and explore early trends that could impact CF care delivery as needs change.
- Many services innovate to address staffing challenges and should continue to be encouraged and enabled to share learning from the changes they made with others.[21]

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

21 The Cystic Fibrosis Trust QI team are available to support CF centres with this work. They can be contacted at **QI@cysticfibrosis.org.uk**

Service-level recommendations

All CF centres that contributed to the staffing tool have been 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 to better understand how their staffing levels compare.

If a service identifies any specific issues with 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 staff groups but lack others entirely.

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 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 UKCF Registry and participation in the staffing tool, as well as future cycles of patient-experience surveys.

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

- 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 longstanding vacancies in a staff group 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 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.

The staffing tool has repeatedly shown that not all people with CF consistently have access to a full specialist MDT and that staff time and resilience is also limited, particularly for psychosocial staff groups and pharmacy. CF teams continue to report shifts in population needs that service models have not kept pace with, high workloads for existing staff, as well as issues with recruitment and retention.

Cystic Fibrosis Trust will continue to work with CF centres to explore and address staffing challenges on a local level. For example, we can support data deep-dives, facilitate planning of targeted quality improvement activities, or help develop 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 helpful[22].

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 **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.
- **Benefits support and income maximisation service** – financial entitlement checks and support with applying for benefits, such as DLA, PIP or Universal Credit
- **Youth programme** – a dedicated programme of events and activities for children and young people with CF and their siblings
- **CF Forum** – an online space to connect with others living with or affected by CF
- **CF Connect** - peer support service for parents of children with CF
- **Work Forwards** – one-to-one support from employment experts, support with employment rights, and group sessions to learn key employability skills.
- **Helen Barrett Bright Ideas Awards** to help people with cystic fibrosis turn their hobbies into new businesses.

We will continue to monitor staffing levels in CF centres through our annual 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, particularly in light of new standards and service specifications, which are expected to be published soon. An updated version of this report will be published in March 2025.

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

22 Cystic Fibrosis Trust, 2024: **https://www.cysticfibrosis.org.uk/the-work-we-do/support-available**

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.e. 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.e. 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	Multi-Disciplinary Team; your CF team made up of each discipline i.e. nurse, physio, social worker, dietitian, etc
Network	A CF centre and its linked clinics form a Network
PREMs	Patient-reported experience measures
QI	Quality Improvement – a framework we use to systematically improve the ways care is delivered to patients
QI WG	Quality Improvement Working Group – a group of health professionals and people with CF/family members working to improve the way care is delivered to those living with cystic fibrosis
Range	Smallest to largest value in a series
Standards of Care	The Cystic Fibrosis Trust's recommended best practice guidelines for CF services (published 2011)
WTEs	Whole-Time Equivalents (also sometimes called 'Full-Time Equivalents'; FTEs)

Cystic Fibrosis Trust

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

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

cysticfibrosis.org.uk

Uniting for a life unlimited