

UK Cystic Fibrosis Service Resourcing 2020 to 2022

Based on findings from the annual Cystic Fibrosis Trust staffing tool

Jana Witt, Sophie Lewis, Sarah Clarke

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Report prepared by

Jana Witt, Clinical Quality Improvement Manager
Sophie Lewis, Clinical Quality Improvement Advisor
Sarah Clarke, Associate Director of Data & Quality Improvement

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Contact information

For more information or feedback about this report, contact: QI@cysticfibrosis.org.uk

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Summary

Participation

In October 2022, 43 of 60 CF centres across the UK completed the Cystic Fibrosis Trust staffing tool. This included 25 paediatric and 18 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 2020, 2021 and 2022), focused mainly on data from October 2022.

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 psychosocial support from CF specialist clinical psychologists and social workers:
 - 10 of 43 participating CF centres (23%) reported not having any active CF clinical psychologists in their MDT.
 - 29 of 43 participating CF centres (67%) reported not having any active CF specialist social workers 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 appear to struggle more with open vacancies.
- In October 2022, median staff time available in paediatric centres was similar compared to adult CF centres in our sample for 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 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.
- Medical, physiotherapy, and dietetics staff time was similar for paediatric and adult populations, but more nursing time was available to paediatrics, whereas adults had slightly more social work, pharmacy and research staff time.
- Similar to the NHS overall, CF services are facing issues with vacancies and recruitment. In October 2022, the vacancy rate in participating CF centres was slightly higher than the NHS vacancy rate overall at 10.5% versus 8.9%.
- 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.
- Satisfaction with staffing levels among responding services remained relatively low year-on-year, with only a quarter saying they were 'satisfied' with staffing in their service in October 2022.
- 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 across the UK adapt and innovate to mitigate staffing challenges and to 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.

Background

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 Care¹ 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 both are currently under review.

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 2011 to 2021, the proportion of people with CF aged 16 or over has increased, with the median age of the CF population in 2021 at 21 years.⁴ Furthermore, median predicted survival age has increased steadily, so that half of people born with CF in 2021 are now predicted to live at least into their fifties.

To continue this trend of ongoing improvement, it is essential to ensure that CF centres have sufficient staff to meet evolving population needs 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 life fulfilled. 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 services 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: 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 2021, published Sep2022: www.cysticfibrosis.org.uk/registryreports

5 NHS England & NHS Improvement, We are the NHS: People Plan for 2020/21 – Action for us all; 2020: www.england.nhs.uk/publication/we-are-the-nhs-people-plan-for-2020-21-action-for-us-all/

6 The Health Foundation, NHS Workforce Projections, Jul 2022: www.health.org.uk/publications/nhs-workforce-projections-2022

7 Nuffield Trust, NHS Workforce; Oct 2022: www.nuffieldtrust.org.uk/resource/the-nhs-workforce-in-numbers

Scope of the report

This report presents an overview of staffing information collected once annually for three years (2020-2022) from participating CF centres across the UK. It is specifically focused on staff time funded from the CF budget 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 CFTR modulators are introduced to increasing proportions of the population, alongside dramatic changes in digital health offerings⁸ 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 2022 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 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, as well as the size of the populations they care for, varied year-on-year. Clinics that enter their own Registry data can individually contribute to the tool, but responses are combined with their network centre in analyses.

Over 70% of CF centres in the UK contributed 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 43 of 60 CF centres (71.7%) in the UK in October 2022, 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=32), the number of participating services varied, and some services contributed data in just one or two years.

The data collected constitute a snapshot of staffing resource 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 regards 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.

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

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

	2020	2021	2022
Paediatric centres	63.6% (21 of 33) Full care: 1,884 Shared care: 1,267	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
Adult centres	78.6% (22 of 28) Full care: 4,502 Shared care: 231	82.1% (23 of 28) Full care: 5,655 Shared care: 166	64.3% (18 of 28) Full care: 3,555 Shared care: 239
Total centres	70.5% (43 of 61) Full care: 7,344 Shared care: 1,498	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

*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 from centres

[^]from 2021 there were 60 CF centres: 56 centres (with local networks) and 4 stand-alone sites; one former paediatric centre joined another's network and hence is no longer counted as a centre in its own right

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, direct comparison of these to the proposed levels in the Trust's Standards of Care⁹ is not recommended. Firstly, the Standards' WTE recommendations suggest slightly different staffing levels for differently sized services and clearly 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, that need to be taken into account when exploring what level of staffing is appropriate in a service. Secondly, the current Standards focus on CF specialist staff only, while this report at times also includes other staff funded through CF budgets who are providing services to CF patients, such as healthcare assistants and welfare advisers. Additionally, some CF MDTs will also have access to other specialist staff who are not funded through CF budgets but who can be invited to input when needed. Such staff would not be captured within the staffing tool.

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. In our first round of data collection for the staffing tool, we found that there was great variation in the way that CF teams described their structures and resources, making it difficult to pool data together and to 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 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.

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

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 service's setup. As a result, some centres have chosen to focus only on their centre's core CF MDT staff, while others also report on CF clinic staff.

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 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 therefore be referred to for the most up to date information.

We will continue to develop and improve our staffing tool and reports in future, 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.

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 group or specialty. "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 any 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 2020		October 2021		October 2022	
	Percent	Centres	Percent	Centres	Percent	Centres
Medical (Doctors)	100%	21 of 21	100%	26 of 26	100.0%	25 of 25
Nursing	100%	21 of 21	100%	26 of 26	100.0%	25 of 25
Physiotherapy	100%	21 of 21	100%	26 of 26	100.0%	25 of 25
Dietetics	100%	21 of 21	100%	26 of 26	96.0%	24 of 25
Psychology	76.2%	16 of 21	76.9%	20 of 26	80.0%	20 of 25
Social Work	33.3%	7 of 21	30.8%	8 of 26	32.0%	8 of 25
Pharmacy	71.4%	15 of 21	80.8%	21 of 26	84.0%	21 of 25
Admin	95.2%	20 of 21	84.6%	22 of 26	92.0%	23 of 25
Research	23.8%	5 of 21	30.8%	8 of 26	44.0%	11 of 25
Other ¹⁰	19.0%	4 of 21	19.2%	5 of 26	20.0%	5 of 25

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 2020		October 2021		October 2022	
	Percent	Centres	Percent	Centres	Percent	Centres
Medical (Doctors)	100%	22 of 22	95.7%	22 of 23	100.0%	18 of 18
Nursing	95.5%	21 of 22	95.7%	22 of 23	100.0%	18 of 18
Physiotherapy	95.5%	21 of 22	95.7%	22 of 23	100.0%	18 of 18
Dietetics	95.5%	21 of 22	95.7%	22 of 23	100.0%	18 of 18
Psychology	77.3%	17 of 22	82.6%	19 of 23	72.2%	13 of 18
Social Work	50.0%	11 of 22	56.5%	13 of 23	33.3%	6 of 18
Pharmacy	86.4%	19 of 22	87.0%	20 of 23	100.0%	18 of 18
Diabetes	Not included		Not included		44.4%	8 of 18
Admin	90.9%	20 of 22	91.3%	21 of 23	100.0%	18 of 18
Research	54.5%	12 of 22	65.2%	15 of 23	50.0%	9 of 18
Other ¹⁰	18.2%	4 of 22	43.5%	10 of 23	61.1%	11 of 18

¹⁰ "Other" represents roles such as: Health Care Assistants, Pulmonary Physiologists, Respiratory Technicians, Welfare Advisors and Youth Workers

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 a full MDT at their CF centre (Table 2). This particularly applied to CF specialist clinical psychologists, social workers and pharmacists, whose availability could change year-on-year and varied between centres. 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.

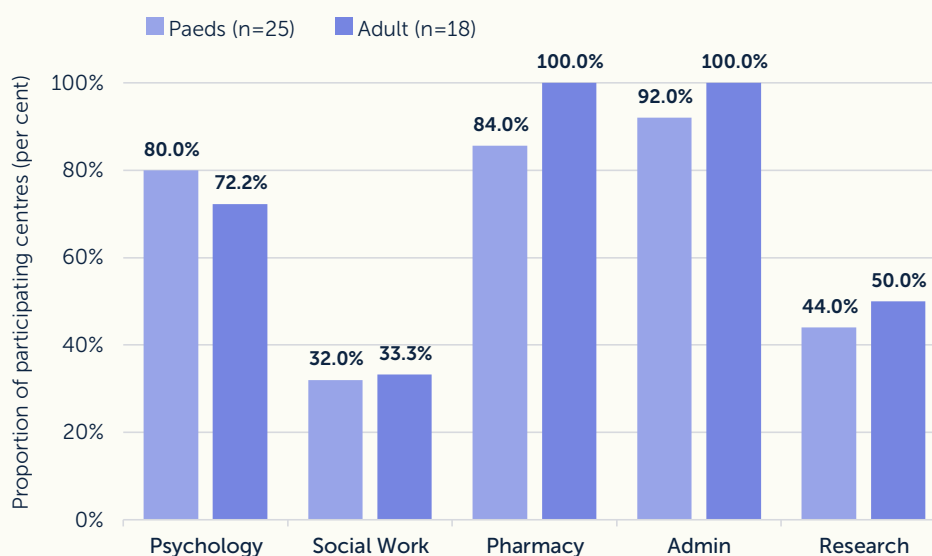
Similar to services for children, all participating adult centres confirmed that their MDT included CF specialist medical, nursing, physiotherapy, and dietetics staff in October 2022 (Table 3). Furthermore, all participating adult centres confirmed they had pharmacy staff available, which had not been the case in previous years' samples, but may simply be due to the smaller sample (n=18) in 2022. Access to CF specialist psychologists and social workers was variable in adult services. In October 2022, for CF psychologists, this was due to open vacancies in five adult CF centres, whereas for social work, this was more often due to a service not having any funded CF social worker roles within their MDT. Diabetes staff were included as their own group for the first time in 2022 and are only shown for adult centres. Eight of 18 adult CF centres (44%) said they had dedicated diabetes staff in their CF MDT.

Overall, nearly all participating CF centres confirmed that 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 and access the most.¹¹ However, other expertise important for holistic CF care was not always available, either because a role was vacant or because there were no funded roles within a staff group. This means that some people with CF may struggle to access certain specialist staff when they need them.

Insight: Not all people with cystic fibrosis consistently have access to a full multidisciplinary team at their CF centre, particularly when it comes to psychosocial support from CF specialist clinical psychologists and social workers.

When comparing availability of staff groups between paediatric and adult services, there was a higher proportion of centres for adults reporting access to pharmacy, admin and research staff in their CF MDT. In previous years, this was also true for psychologists and social workers. However, in the latest data from October 2022, a lower proportion of participating adult centres had access to CF psychologist input (72.2% of adult centres vs. 80% of paedics centres) due to several vacancies in this staff group. The proportion of centres with access to CF social worker input was similar between participating paediatric and adult services in October 2022 (32% of paediatric centres and 33.3% of adult centres had a CF social worker).

Figure 1: Proportion of paediatric and adult CF MDTs with active psychology, social work, pharmacy, admin and research staff in Oct 2022



11 Cystic Fibrosis Trust, Patient-Reported Experience Measures; 2022 www.cysticfibrosis.org.uk/QI

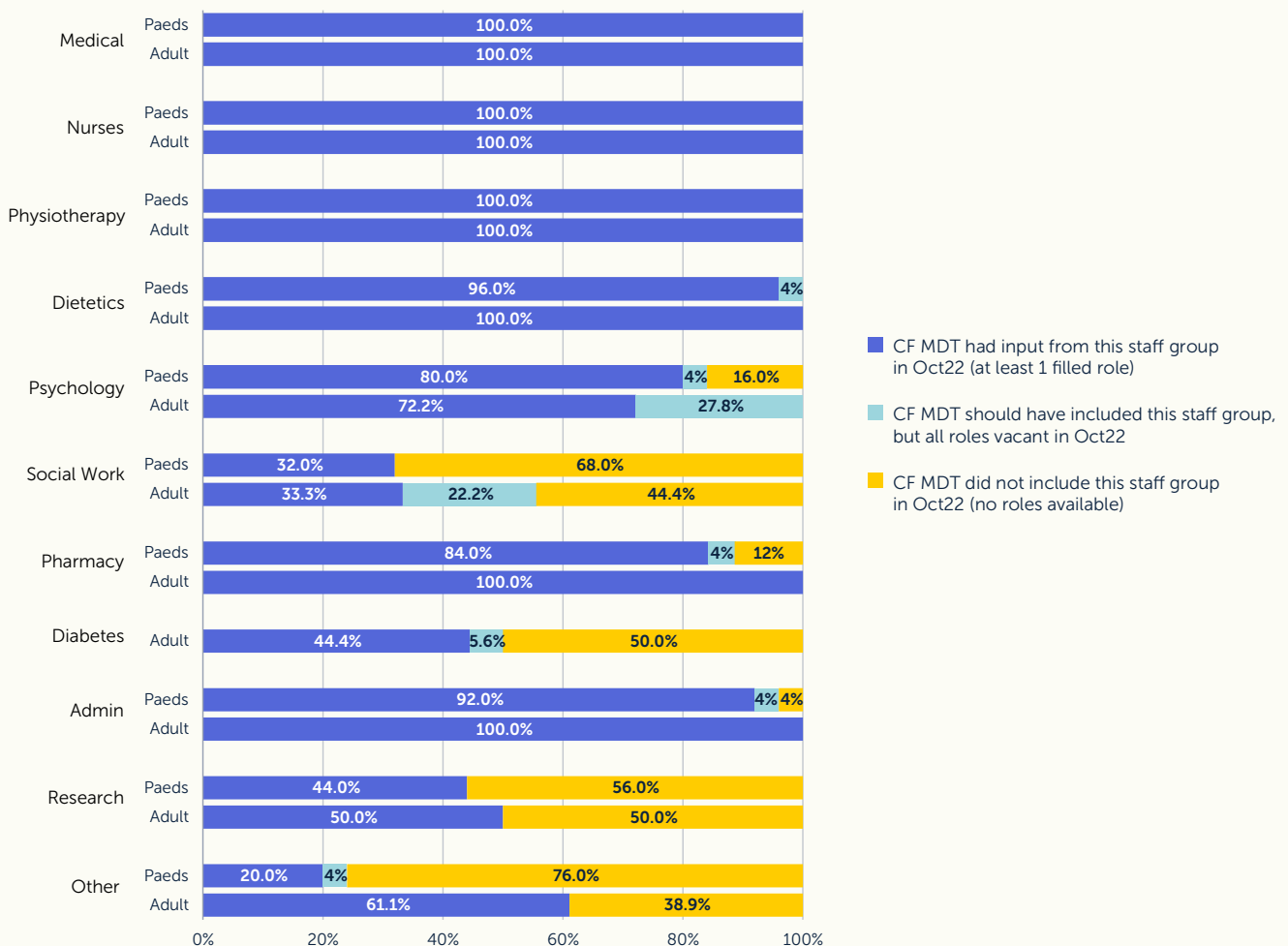
The proportions of CF centres that included psychologists, social workers, pharmacists, administrators, or research staff in their MDT varied between paediatric and adult centres. Availability of these staff groups was more easily impacted by vacancies compared to other groups. This is likely because there was often only one role in each of these staff groups within each centre. When that role was vacant, there was no input from this staff group into the CF MDT, unless appropriate cover was in place. However, 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 a lack of funding for roles in certain staff groups. 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 2022, 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 five of these (27.8%) temporarily lacked input from this staff group in the CF MDT due to these roles being vacant. It also shows that four participating adult CF centres (22%) lacked specialist CF social worker input in the short term, as they had open vacancies for social workers. In contrast, services for children were more likely to not have any specialist roles available for CF-specialist psychologists and social workers in their MDTs.

Figure 2: Availability of staff groups in CF MDTs

NB: The below is based on data from participating paediatric (n=25) and adult (n=18) CF centres



Insight: A slightly larger proportion of paediatric CF services appear to lack certain staff groups in their MDT compared to adult CF centres, which appear to struggle more with open vacancies.

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, and characteristics of the patient population, as well as 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 ability to meet professional standards and improved clinical outcomes. Staffing information provides important insights to help teams explore whether the level of staffing in their service is appropriate, and to track how it changes over time.

In order 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 WTE cover per 75 patients from this. This approach 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 readily.

Table 4: Median centre-level staff time available by staff group in 2022

NB: The table below shows the median WTE available per 75 patients in participating paediatric and adult centres in October 2022; 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 Centres (n=25)		Adult Centres (n=18)	
	Median* WTE / 75 patients	Range** Lowest – Highest	Median* WTE / 75 patients	Range** Lowest – Highest
Medical (Doctors)	0.9	(0.2 – 1.9)	0.6	(0.4 – 1.4)
Nursing	1.8	(0.4 – 2.7)	1.3	(0.3 – 3.2)
Physiotherapy	1.3	(0.5 – 2.5)	1.2	(0.5 – 2.1)
Dietetics	0.6	(0.0 – 1.1)	0.6	(0.3 – 0.8)
Psychology	0.3	(0.0 – 0.8)	0.2	(0.0 – 0.6)
Social Work	0.0	(0.0 – 1.0)	0.0	(0.0 – 0.7)
Pharmacy	0.2	(0.0 – 0.8)	0.4	(0.1 – 0.6)
Diabetes	Not reported		0.0	(0.0 – 0.4)
Admin	0.7	(0.0 – 1.3)	0.6	(0.0 – 1.1)
Research	0.0	(0.0 – 0.6)	0.1	(0.0 – 0.7)
Other	0.0	(0.0 – 0.7)	0.2	(0.0 – 0.7)

* 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)

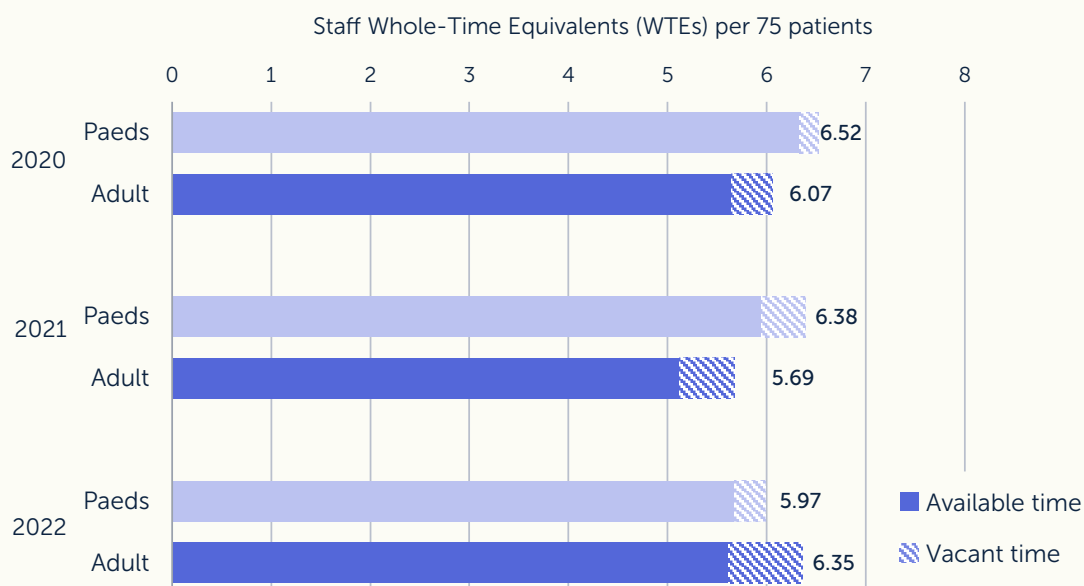
** The range shows the lowest and highest staffing level seen among participating centres for each staff group (as WTE per 75 patients); it gives an idea of the differences in level of cover between different centres, but does not take fully into account differences in patient population characteristics or complexity, nor external / other factors that can impact on required staffing levels

Insight: In October 2022, median staff time available in paediatric centres was similar compared to adult CF centres in our sample for 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 centres.

The different amounts of staff time available across participating centres (see ranges in Table 4) 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: Average staff time available in October 2020, 2021 and 2022

NB: Average staff time was calculated based on all posts (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)



Overall staff time for paediatric and adult populations served by participating CF centres was relatively similar year-on-year (6-6.5 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 on available staff time each year, as a proportion of funded roles remain uncovered and are not available to deliver care. Adult centres consistently had a higher proportion of vacant staff time compared to paediatric centres.

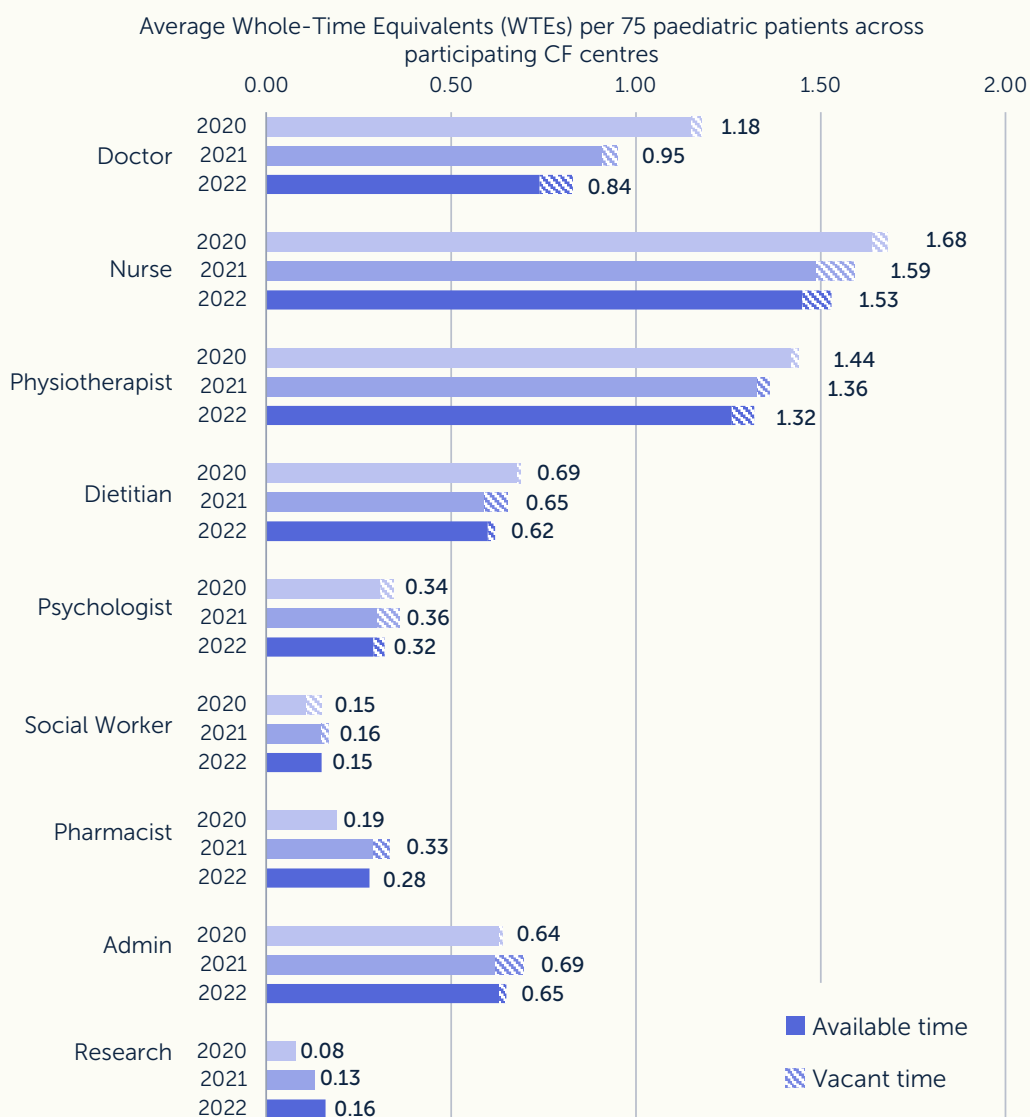
Insight: Overall staff time available to the CF population across participating centres fluctuates and it will be vital to monitor this in future

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 sample; 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)

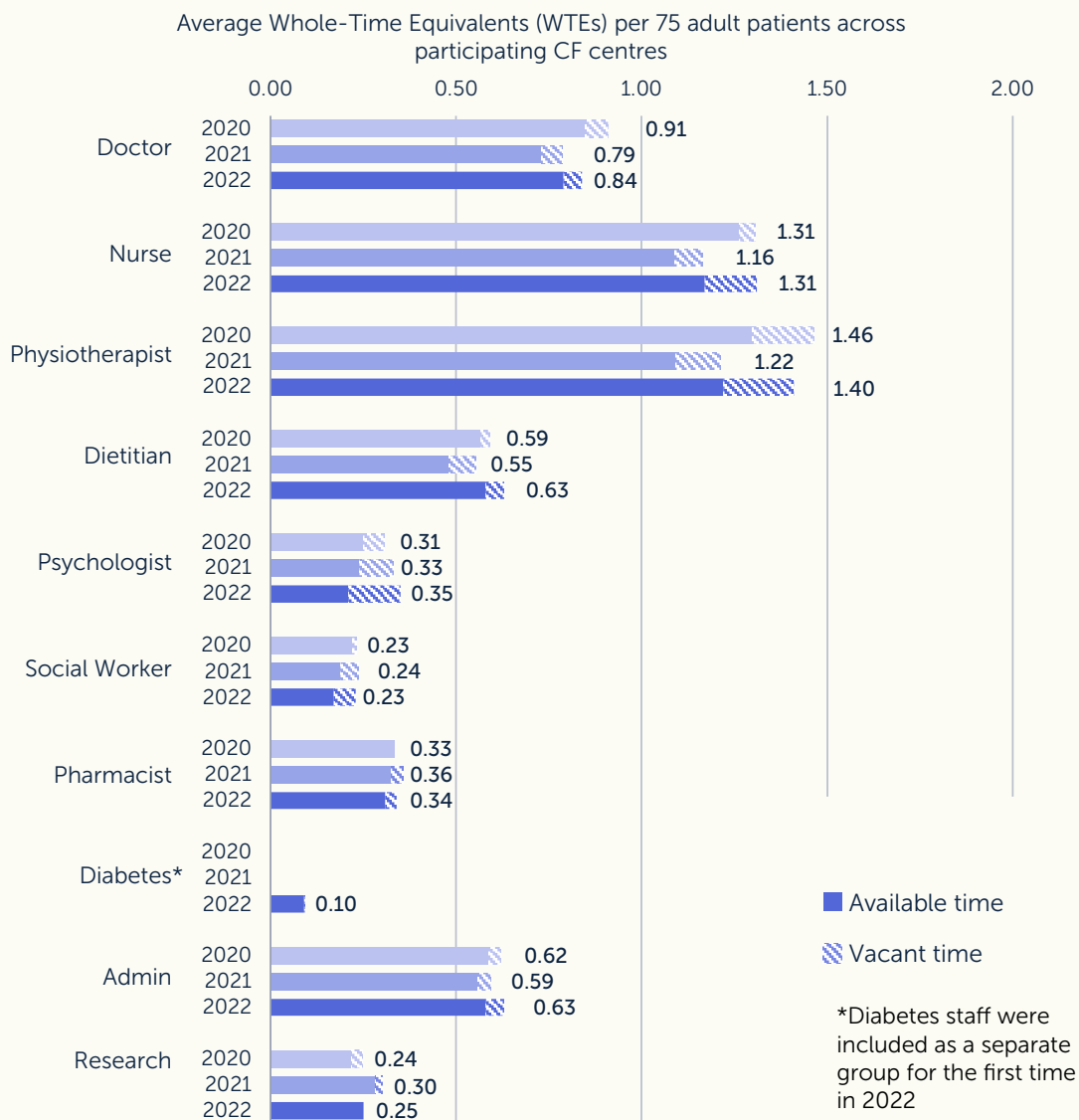


The average medical, nurse, physiotherapy and dietetics WTEs available to the paediatric CF population in participating services appear to have reduced year-on-year (Figure 4). This is particularly notable for doctors. While all participating paediatric services had confirmed they had roles in these staff groups (Table 2) in October 2022, overall time available to the population appears to have decreased.

In other staff groups, including psychology and social work, WTE available appear to have remained relatively stable year-on-year, but often at much lower levels than for the top four staff groups (Figure 4). It is also important to reiterate that not all centres had roles available for these staff groups (Table 2).

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)



In October 2022, average CF specialist medical, physiotherapy and dietetics WTEs available to the adult CF population in participating services was similar to the paediatric population (Figures 4 and 5). This had generally been lower for the adult population than the paediatric population in previous years.¹² While a trend of decreasing staff time in these staff groups had been observed between October 2019 and 2021 across participating adult services, this was not continued in our sample in 2022 (Figure 5).

Similar to findings from paediatric centres, average WTEs available for adult CF psychology, social work and pharmacy remained relatively stable year-on-year and 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, with eight adult CF centres reporting staff in this group who provided dedicated input into the CF MDT. The overall WTEs per 75 patients across our full sample are therefore relatively low (0.10), and as with psychosocial staff groups, it is important to reiterate that not all centres had diabetes staff available (Table 3).

Insight: Medical, physiotherapy, and dietetics staff time was similar for paediatric and adult populations, but more nursing time was available to paediatrics, whereas adults had slightly more social work, pharmacy and research staff time.

12 Cystic Fibrosis Trust, Staffing Report 2020-2021; Jun2022: UK Cystic Fibrosis Service Resourcing – Report June 2022

When looking at average staff time available, it is important to consider context. For example, in October 2020 and 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, particularly in adult CF services, unless there was an uplift in roles and/or WTEs within CF services to match changes in patient numbers.

Future 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 CFTR modulator drugs, as well as the digitalisation of the NHS and increased use of remote consultation formats.

Staff seniority

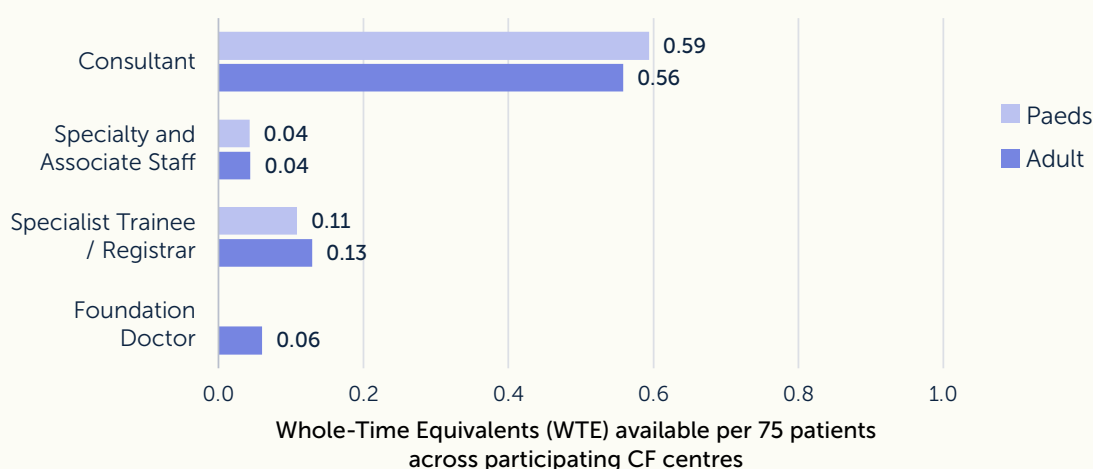
Staffing levels vary not only by the types of roles and overall staff time available, but also by the seniority of such roles. In 2019, participating adult centres had a significantly higher proportion of lower-banded posts than paediatric centres (24.1% vs. 12.8%). While adult centres still had a larger proportion of posts at Band 5 or below in October 2022 (17.3% vs. 14.4%), this difference was no longer as pronounced, which aligns with what was observed in 2021 as well.

Figures 6 to 15 show staff time available across children and adults with CF under the care of participating services in October 2022 (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 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 individually and split by seniority (NHS banding).¹³ 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.

Figure 6: Medical staff time available per 75 patients by banding Oct 2022

NB: Based on 0.74 (paeds) and 0.79 (adult) WTE per 75 patients medical staff time



13 NHS England, Agenda for Change; 2022: Agenda for change – pay rates, Health Careers

Figure 7: CF Nursing staff time available per 75 patients by banding Oct 2022

NB: Based on 1.45 (paeds) and 1.17 (adult) WTE per 75 patients nurse staff time

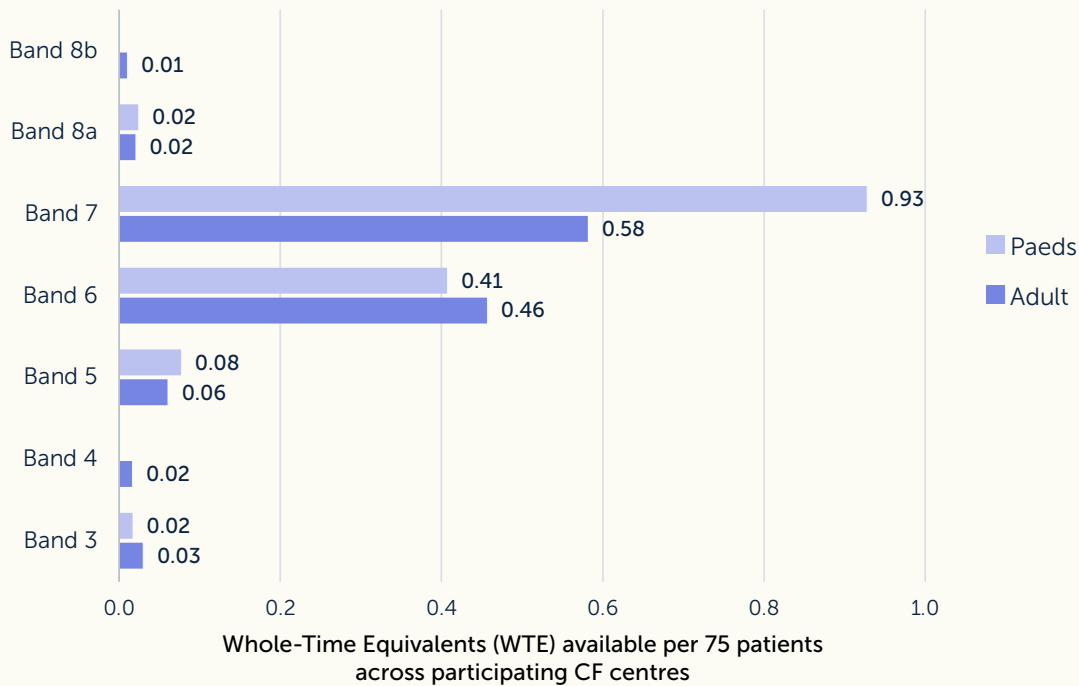
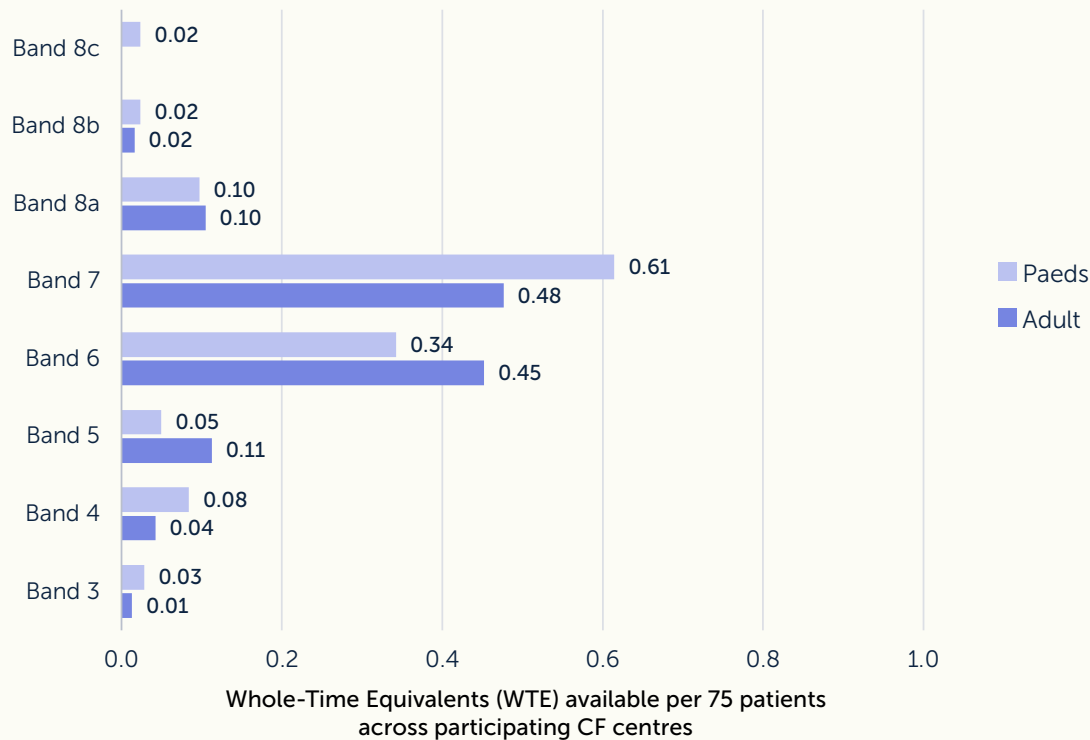


Figure 8: CF Physio staff time available per 75 patients by banding Oct 2022

NB: Based on 1.26 (paeds) and 1.22 (adult) WTE per 75 patients physio staff time

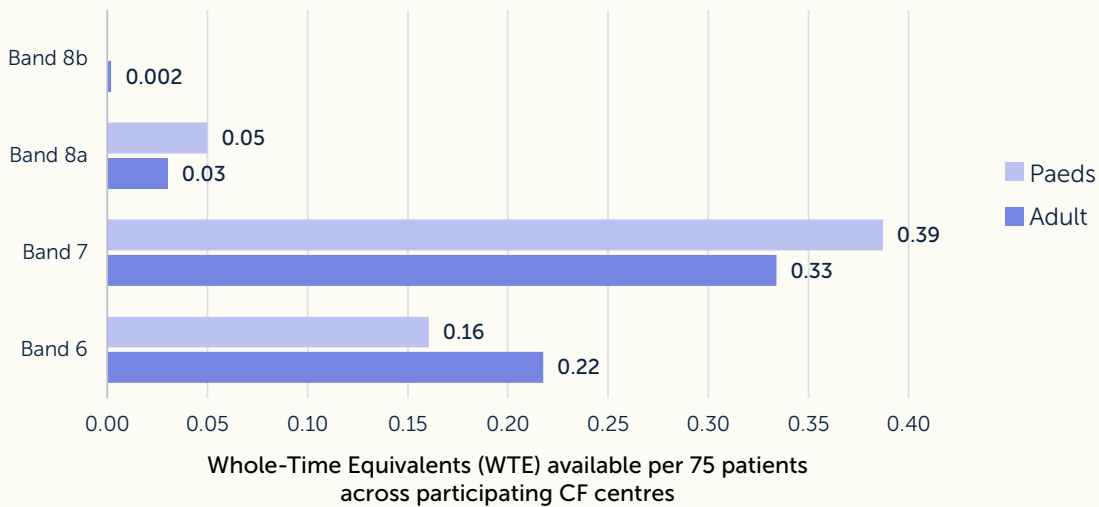


Specialist CF medical (Figure 6), nursing (Figure 7) and physiotherapy (Figure 8) staff were the three groups with the most staff time available overall. Banding for doctors differs from other NHS staff banding, with most medical staff in CF centres employed at Consultant level (Figure 6). The most junior medical roles (Foundation Doctors) were only available in adult CF centres. Similar to our findings in previous years, the majority of nurses and physiotherapists were employed at Bands 6 or 7.

For all three groups, our findings show that there was slightly more senior staff time available to the paediatric population, compared to adults, although this was marginal for doctors in October 2022.

Figure 9: CF Dietetics staff time available per 75 patients by banding Oct 2022

NB: Based on 0.60 (paeds) and 0.58 (adult) WTE per 75 patients dietetics staff time
 NB: One Band 3 post not shown (<0.005 WTE/75 patients)



Similar to nurses and physios, CF dietitians tended to be employed at Bands 6 or 7, with more senior staff time available in paediatric services at Bands 7 and 8a.

Figure 10: CF Psychology staff time available per 75 patients by banding Oct 2022

NB: Based on 0.29 (paeds) and 0.21 (adult) WTE per 75 patients psychology staff time
 NB: One Band 4 post not shown (<0.01 WTE/75 patients)

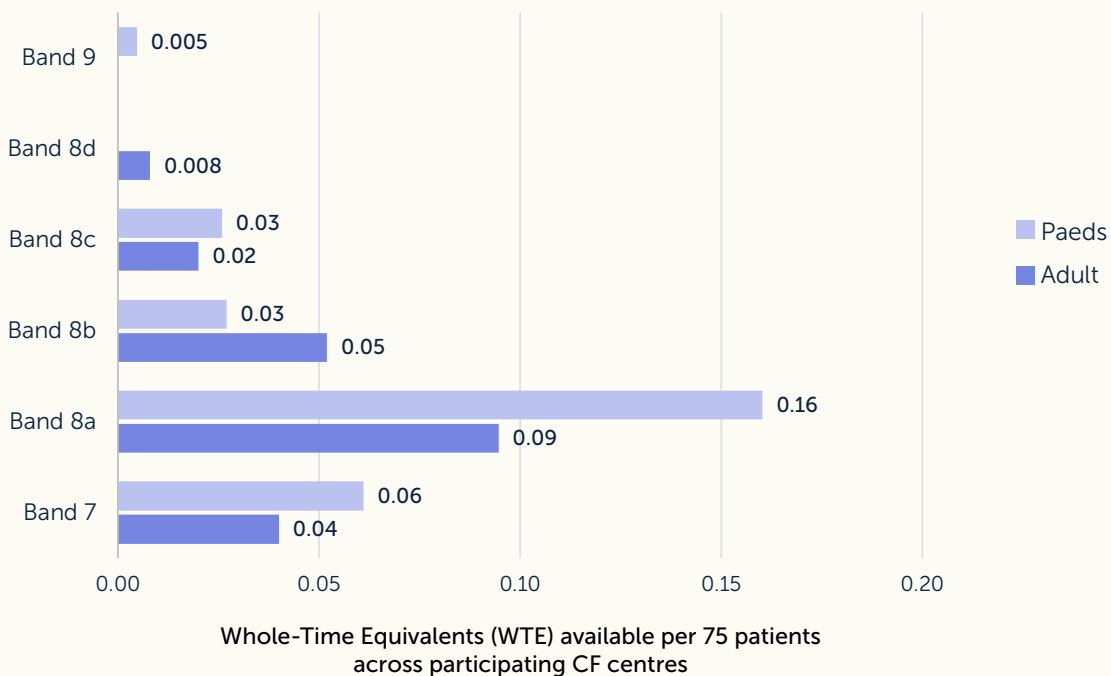


Figure 11: CF Social work staff time available per 75 patients by banding Oct 2022

NB: Based on 0.15 (paeds) and 0.17 (adult) WTE per 75 patients social work staff time

NB: One Band 3 post not shown (<0.001 WTE/75 patients)

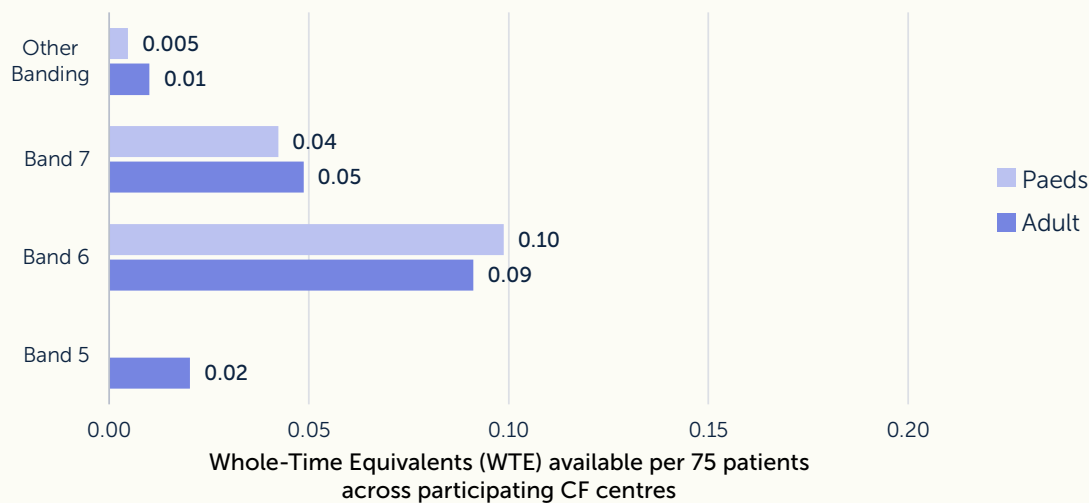
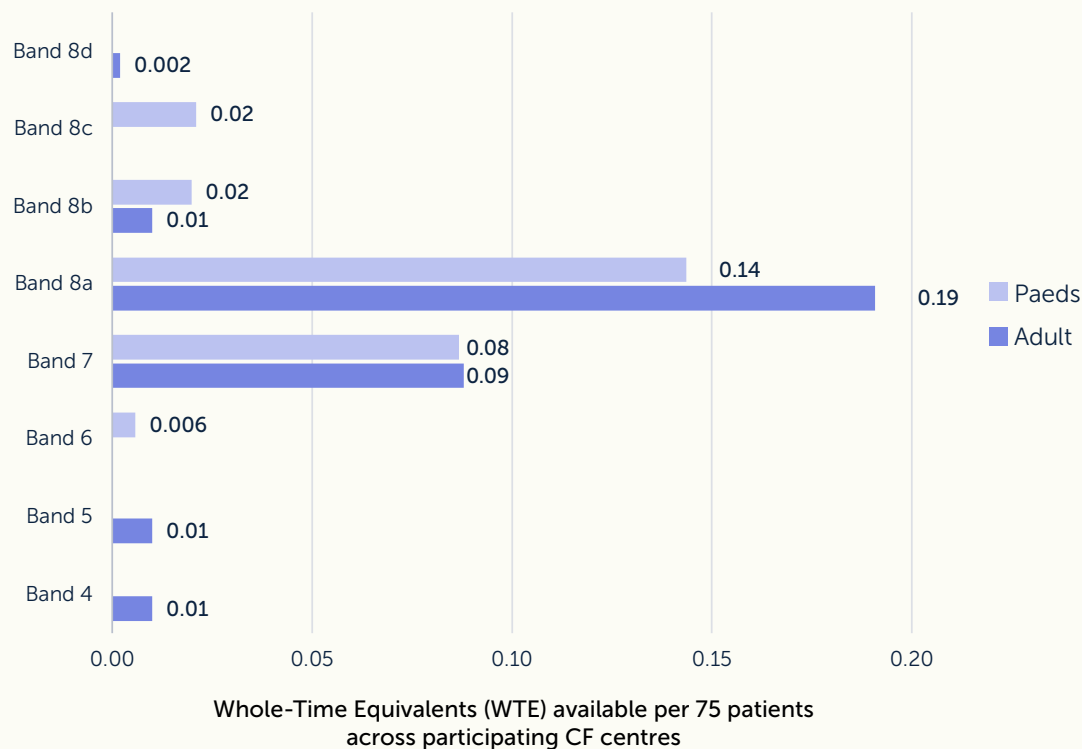


Figure 12: CF Pharmacy staff time available per 75 patients by banding Oct 2022

NB: Based on 0.27 (paeds) and 0.31 (adult) WTE per 75 patients pharmacy staff time



For CF psychologists, social workers, and pharmacists, 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 2022, which impacts average WTE available (Tables 2 and 3).

In addition to psychosocial and pharmacy staff, the staffing tool also asked about diabetes staff in CF MDTs. Figure 13 shows average diabetes staff time available per 75 patients across the adult population in our sample. It is important to keep in mind that only 44.4% of adult services (n=8) said they had dedicated diabetes staff in their CF MDT, which is shown here. Other teams may have access to diabetes staff input through the specialist diabetes service or may refer into such services.

Figure 13: Diabetes staff time available per 75 patients by banding Oct 2022

NB: Based on 0.09 (adult) WTE per 75 patients diabetes staff time

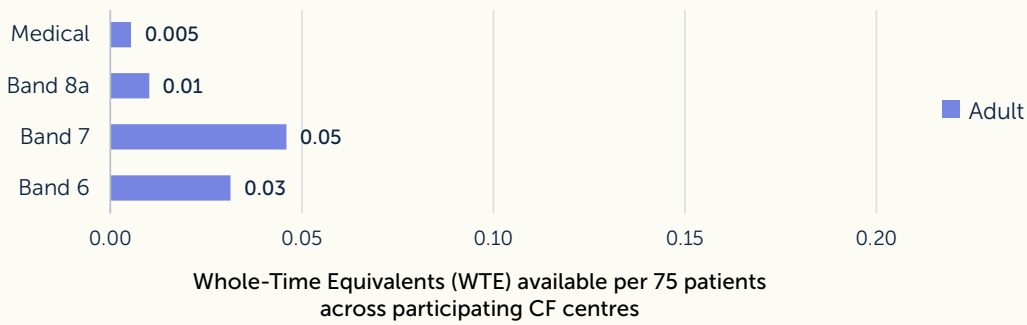
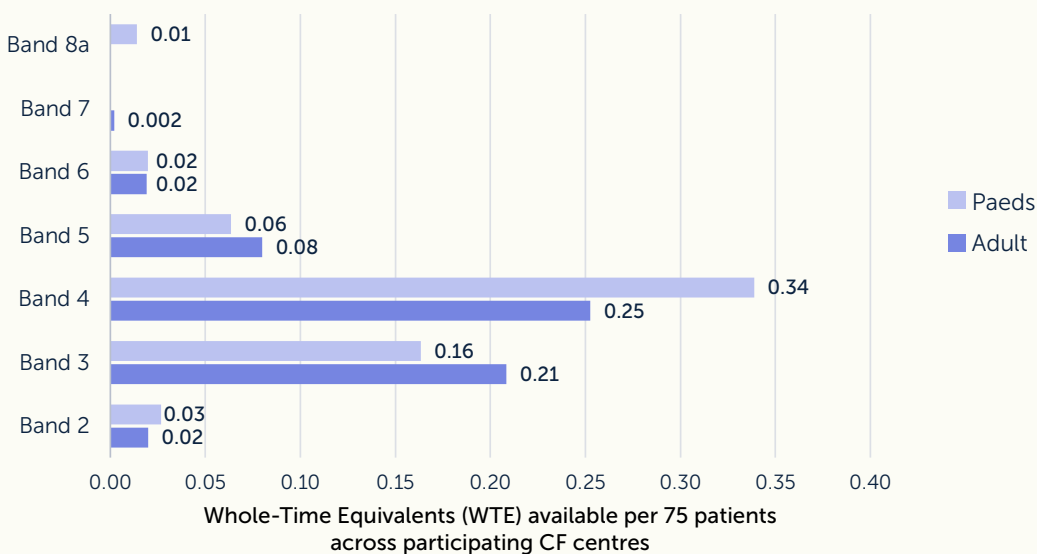


Figure 14: Admin staff time available per 75 patients by banding Oct 2022

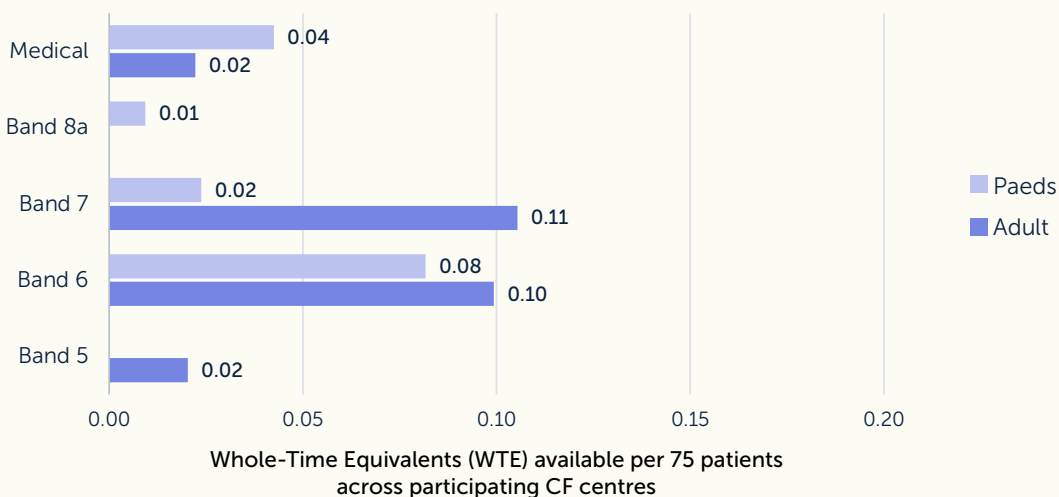
NB: Based on 0.63 (paeds) and 0.58 (adult) WTE per 75 patients admin staff time



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

Figure 15: Research staff time available per 75 patients by banding Oct 2022

NB: Based on 0.16 (paeds) and 0.25 (adult) WTE per 75 patients research 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, but a larger proportion of paediatric research staff were employed at Band 8a or medical bands (32.5% vs. 8.9%), indicating they tended to be more senior. However, just under half of participating CF centres in our sample in 2022 (20 of 43) said they had dedicated roles for research staff within their CF MDTs.

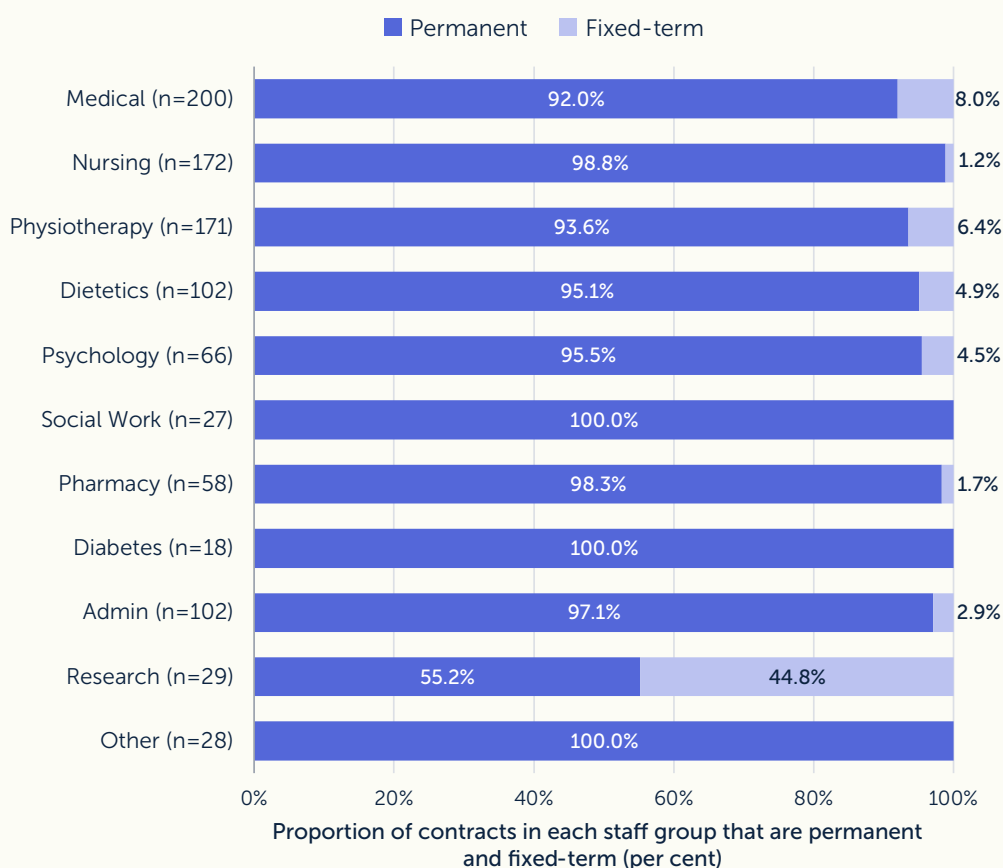
Research staff can ensure that clinical trial opportunities are presented in a timely way to people living with CF, which may result in improved access to the latest therapies.¹⁴ It is important to note that, even where services did not report access to dedicated CF research staff within their MDT, they may be able to access other research staff within their NHS Trust, which would not be captured by the CF staffing tool.

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 2022 was 5.5%, while 94.5% of roles had permanent contracts. While five percent 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 973 roles in participating paed and adult centres, regardless of hours worked (WTE)



For all staff groups except research staff, over 90% of contracts in place across participating CF centres were permanent, with only 1.2-8% 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 as these form part of training for doctors. Research staff were the only group that had a substantial proportion of staff on fixed-term contracts in CF MDTs (44.8%).

14 Cystic Fibrosis Trust, 2022: Clinical Trials Accelerator Platform (cysticfibrosis.org.uk)

Section 3

Vacancies

Even when a centre has active staff in each group, it may not be fully staffed. This is exemplified by physiotherapist vacancies in October 2022, where 18 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.

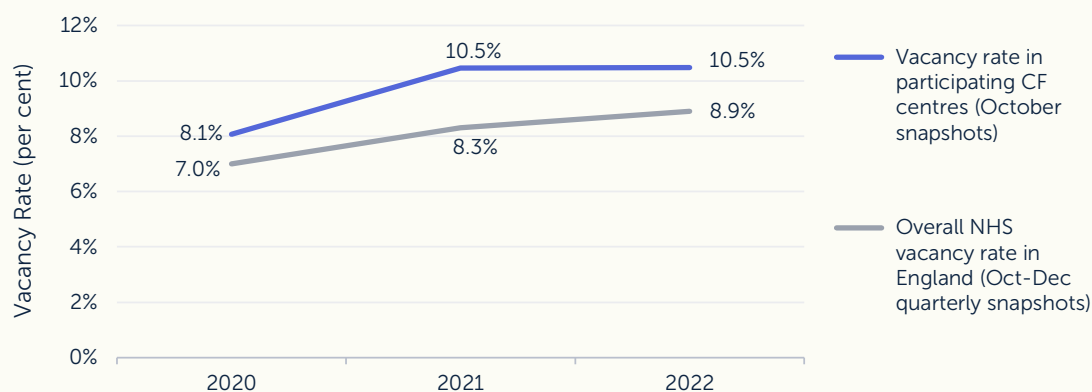
In October 2022, there were 98 vacancies across participating CF centres, with 18 of 25 paediatric and 15 of 18 adult centres reporting at least one vacancy. To better understand how vacancy rates in CF services compare with the NHS overall, the staffing tool collects information on currently active staff in each service, as well as vacant roles and cover arrangements, in the form of Whole Time Equivalents (WTE). Table 5 shows the vacancy rates across participating services over the last three years of the staffing tool. We have adjusted our calculation for vacancy rates this year to better align with NHS Digital’s approach to calculating overall NHS vacancy rates, by excluding temporary cover arrangements.

Table 5: WTE workforce and vacancy rates across participating CF centres

	2020	2021	2022
Planned CF Workforce (WTE)	609.72	688.54	571.27
Vacancies (WTE, incl. covered time)	49.20	72.06	59.78
Vacancy Rate* (%)	8.07%	10.47%	10.46%
Covered Arrangements (WTE)	16.60	11.53	10.13

*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 = active workforce WTE plus vacancies WTE; Vacancy Rate (%) = (Vacancies WTE ÷ Planned WTE) x 100]¹⁵

Figure 17: Vacancy rate changes over time, 2020-2022



In the last quarter of 2022 (October to December), NHS Digital’s Vacancy Statistics¹⁵ showed a vacancy rate of 8.9% across NHS providers in England, compared to a vacancy rate of 10.5% in participating CF centres in October 2022, though it should be noted that some CF centres were located in devolved nations.

15 NHS Digital, NHS Vacancy Statistics England [Experimental Statistics: April 2015 – December 2022 – Tables]; March 2023: NHS Vacancy Statistics (and previous NHS Vacancies Survey) – NHS Digital

Insight: Similar to the NHS overall, CF services are facing issues with vacancies and recruitment. In October 2022, the vacancy rate in participating CF centres was slightly higher than the NHS vacancy rate overall at 10.5% versus 8.9%.

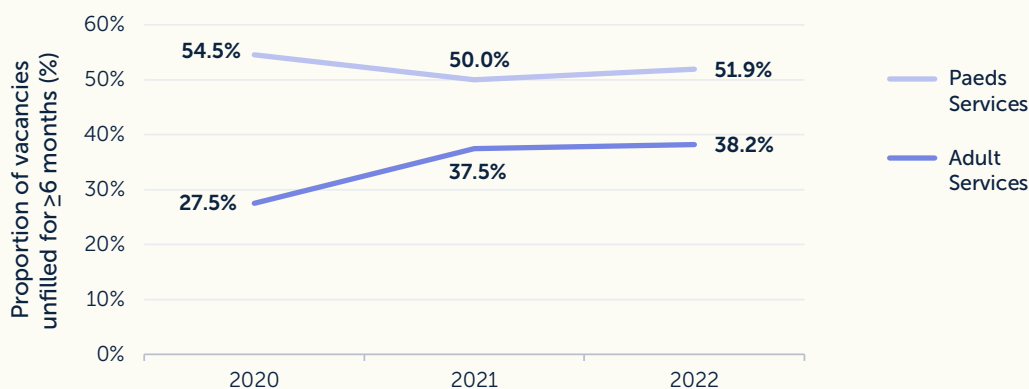
Table 6: Vacancies* unfilled for six months or more by staff group in 2022

	Paeds Services (n=25)			Adult Services (n=18)		
	Proportion vacant ≥ six months	Vacant ≥ six months	Total vacant posts	Proportion vacant ≥ six months	Vacant ≥ six months	Total vacant posts
Medical (Doctors)	57.1%	4	7	40.0%	2	5
Nursing	60.0%	3	5	20.0%	2	10
Physiotherapy	0%	0	4	36.4%	4	11
Dietetics	50.0%	2	4	20.0%	1	5
Psychology	100%	3	3	41.7%	5	12
Social Work	–	0	0	60.0%	3	5
Pharmacy	0%	0	1	50.0%	1	2
Diabetes	Not included			100%	1	1
Admin	50%	1	2	33.3%	1	3
Research	–	0	0	–	0	0
Other	100%	1	1	100%	1	1
Total proportion of vacancies unfilled for six months or more	51.9%	14	27	38.2%	21	55

* 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, half the vacant posts for doctors (6 of 12, 50%) and psychologists (8 of 15, 53%) in CF MDTs had been unfilled for six months or more by October 2022. A higher proportion of vacancies in participating children’s services remained unfilled for more than six months compared to adult services. This finding was consistent with previous years for which we have staffing data and may indicate that paediatric services struggle more to fill vacancies.

Figure 18: Proportion of vacancies that had remained unfilled for ≥6 months

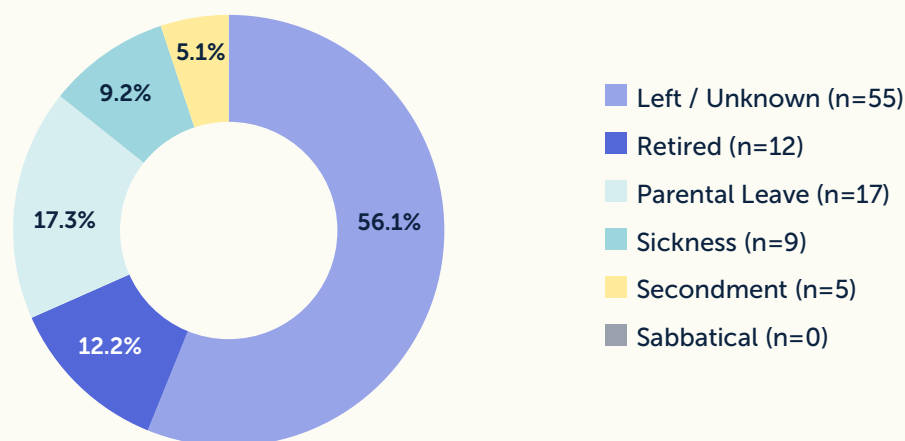


Insight: A higher proportion of vacancies in CF centres for children remained unfilled for six months or longer, while centres for adults reported a higher number of vacancies.

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 2022



Most posts were vacant due to staff having left or retired (68.3%), but nearly 1 in 3 (31.7%) were vacant due to a contracted member of staff on parental or sick leave or on secondment. No staff were reported to be on sabbatical in October 2022.

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 98 vacant posts in October 2022, 16 were covered (16.3%) and of these, 13 (81.3%) were covered at the same or higher WTE level/banding than the vacant, substantive post.

Table 7: Vacancy cover arrangements

	Paeds Services			Adult Services		
	Covered at \geq banding & WTE level	Total covered posts	Proportion covered at same level	Covered at \geq banding & WTE level	Total covered posts	Proportion covered at same level
2020	4	8	50.0%	8	17	47.1%
2021	2	6	33.3%	7	13	53.8%
2022	10	12	83.3%	3	4	75.0%

In contrast to previous years, services seemed to have relatively good proportions of vacancies that were covered at the same level or higher in terms of staff banding and WTE. However, the overall proportion of vacancies that was covered remained low at just 16.3% in October 2022, indicating that most vacancies in CF MDTs are not backfilled.

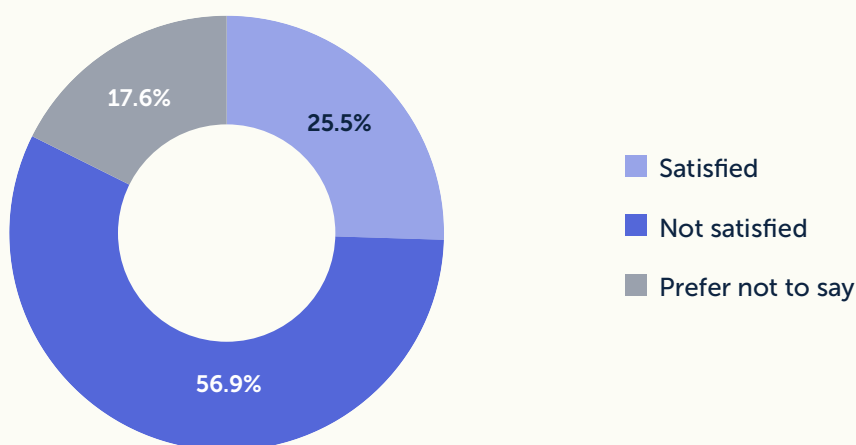
Section 4

Satisfaction with staffing levels

To understand how staff perceive the levels of staffing within their own services, 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 2022

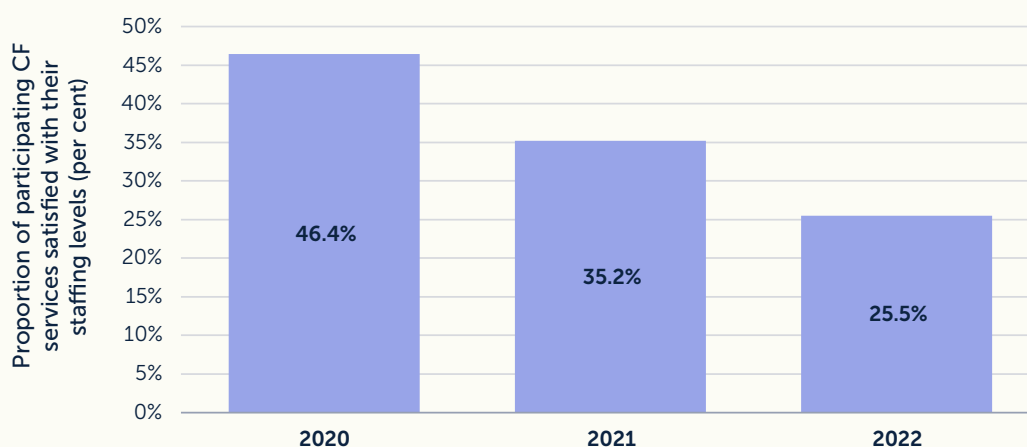
NB: Responses from clinics were counted individually in this calculation; total responses included: 51; 43 CF centres and 8 associated network clinics



In October 2022, satisfaction with staffing levels in CF services was relatively low. More than half (56.9%) of responding services (centres and clinics) said that they were not satisfied with staffing in their service. Only about a quarter (25.5%) said they were satisfied, while 17.6% preferred not to share their views. Services that had reported vacancies were more likely ($p=0.0285$) to say they were dissatisfied than services with no vacancies.

Figure 21: Proportion satisfied with staffing levels each year, 2020-2022

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



Insight: Satisfaction with staffing levels among responding services remained relatively low year-on-year, with only a quarter saying they were 'satisfied' with staffing in their service in October 2022.

Each year, fewer than half of participating services reported that they were satisfied with their staffing levels. Satisfaction was at its lowest in October 2022, possibly reflecting ongoing challenges with staffing across the NHS, although it is important to note that the proportion of 'prefer not to say' responses was at its highest (17.6%), while the proportion 'dissatisfied' remained relatively stable.

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. The proportion 'dissatisfied' with staffing was between 48 and 59%. Dissatisfaction with staffing levels may have been due to open vacancies or a lack of staff more generally, for example due to a lack of funding for certain roles. We will seek to explore this further in future.

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

NB: Percentages below 5% have been rounded to the nearest whole number

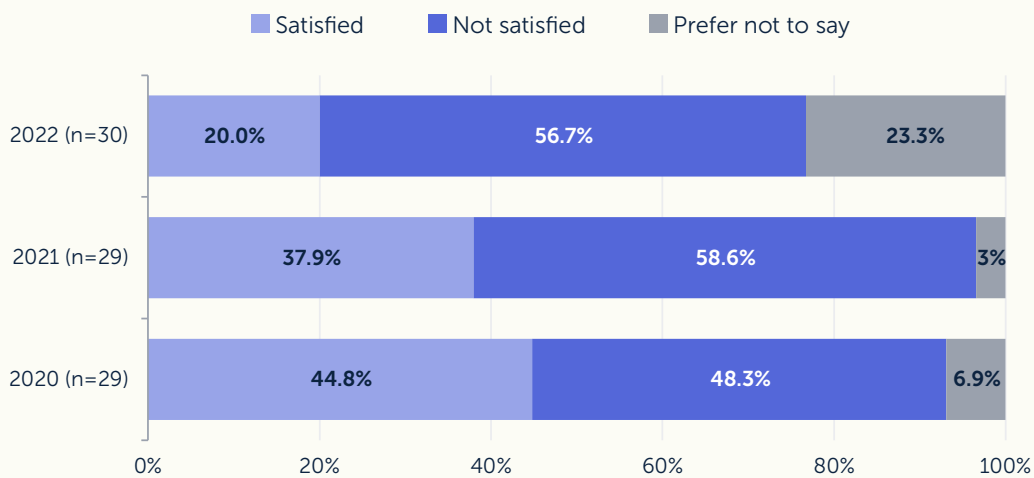
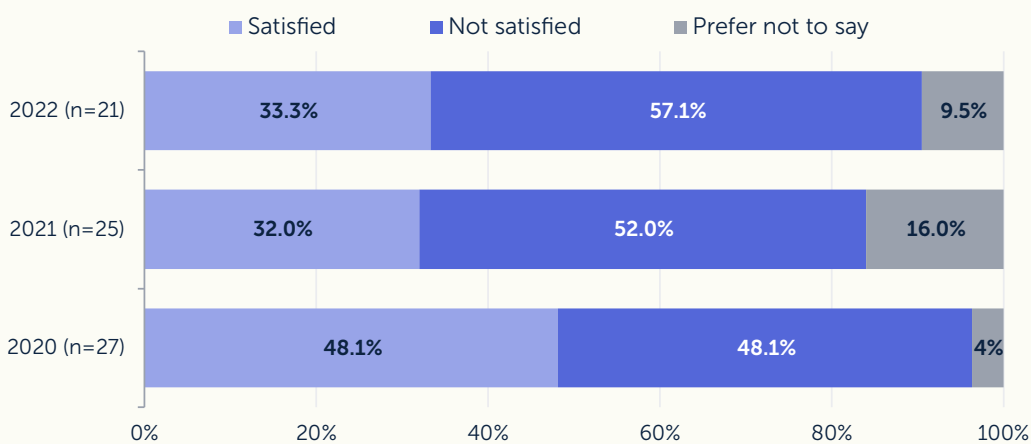


Figure 23: Satisfaction with staffing levels in adult services over time

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

NB: Percentages below 5% have been rounded to the nearest whole number



Section 5

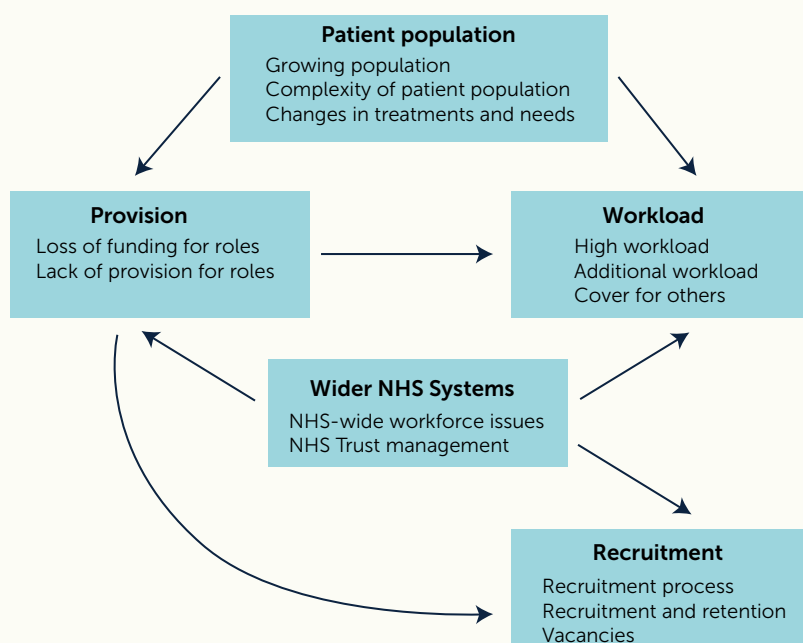
Challenges and innovations

The staffing tool explores satisfaction with staffing levels and asks respondents to share reflections on challenges and innovations in their service.

Staffing challenges

In October 2022, 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 lay 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 October 22.

Figure 24: Factors driving staffing challenges within CF teams



Two of the most common themes mentioned when asked about staffing challenges were vacancies and problems with recruitment. As shown in Section 3 (Vacancies), there were a number of vacancies in CF services, many of which had remained unfilled for long periods. In addition, only a small proportion of vacancies had cover arrangements in place.

"Multiple vacancies and uncertainties about filling vacancies post-COVID and post-modulators." Adult service (Dissatisfied)

"Associate specialist full time CF post currently vacant, increased pressure on service." Paediatric service (Dissatisfied)

"Consultant on maternity leave with no cover. Physio about to go on maternity leave, at present no cover." Paediatric service (Satisfied)

"Vacant psychology post has a negative impact on our patients, meaning we signpost to community services far more. We wonder if the role is too part-time to attract the right applicant." Adult service (Dissatisfied)

Several CF teams shared specific issues they had had with recruitment, including a lack of suitable applicants for roles and particular difficulties finding CF specialist psychologists to fill positions.

"Recruitment is a problem across most of the MDT but specifically Nursing and Physiotherapy. Positions either receive no applicants or those that do apply aren't suitable. This is having an impact on the services we can offer our patients with the withdrawal of the community service at the current time. It is also having an impact on personal development with staff being limited to courses and conferences due to staffing shortages." Adult service (Dissatisfied)

"CF Nurse Specialist retired unexpectedly [...], necessitating a reshuffle of services. No provision for succession planning or recruitment." Paediatric service (Dissatisfied)

"Consultant colleague resigned / retired and has not been replaced. This is not because there is not a willingness to get her replaced but due to the fact that no one wants to apply for the job or there are not people out there to apply!" Paediatric service (Dissatisfied)

"Extremely difficult to recruit to the psychology position. Impact on patients when [they] experience poor mental health. Impact on staff wellbeing when managing distressing situations with little support." Adult service (Dissatisfied)

"Psychology has been problematic with great difficulties recruiting (a national problem), so we have had a shortage for many months, but this has been finally resolved." Paediatric service (Satisfied)

A lack of provision for certain roles, particularly CF clinical psychologists and social workers, was also mentioned by several services as a challenge, either because there was no funding available for such roles, or because a fixed-term funded role had come to an end and had not been renewed. This particularly shone through in comments from paediatric services.

"Not having social work is a disservice with a large ethnic and deprived patient cohort, our nurses' valued time is being used to fill this gap. [...] We have a large number of patients and not enough staff time in each discipline." Paediatric service (Dissatisfied)

"CF Clinical Psychologist retired. The post was not filled as the [local NHS] Trust wanted to review the need for a CF-specific role. This led to ad-hoc psychology support for patients and families from differing psychologists who do not necessarily have specialist CF knowledge." Paediatric service (Dissatisfied)

"We have not secured continued funding of our Adherence champion (interventionist) role. This was an extremely useful role within our team [...] working with families and young people to improve adherence when this was identified as a problem. Such a role will be increasingly important with the increased use of CFTR modulators to ensure that they are adhered to, and other care aspects are addressed when needed to prevent disease progression." Paediatric service (Dissatisfied)

"We have had a lot of changes in psychology and psychology is not a dedicated part of the team. We have to refer to psychology, so access is limited to psychology input." Paediatric service (Dissatisfied)

"We have no social worker. Our CF nurses take on this role in part, which shouldn't be the case." Paediatric service (Dissatisfied)

Unsurprisingly, with workforce shortages not only in CF services, but across the wider NHS, another common theme centred around workload for existing staff, including taking on additional workload and covering for others.

"Social workers again have been pulled to cover emergency consults in ED [Emergency Department] and have not always been available." Paediatric service (Dissatisfied)

"Many members of the CF team are being pulled to cover staff vacancies elsewhere, this is causing a shortage of time available to look after CF patients." Adult service (Dissatisfied)

"CF dietitians being pulled into covering other areas. Psychology, similar to dietetics, remains a challenge for the same reasons. CF physiotherapy is challenging due to shortage of staff in other areas and our physios needing to cover. The impact of all these challenges leads to patients either not being seen as frequently as they should or a delay in them being seen. It may also mean that some of the functions, e.g. exercise testing in physiotherapy, [are] not taking place." Paediatric service (Dissatisfied)

Overall, many of the challenges mentioned by CF teams reflect challenges faced by services across the NHS. However, there were also some challenges specific to cystic fibrosis that were putting additional pressures on CF teams. These included a growing and ageing population with CF, as well as a shift in population needs, due to the increasing availability of CFTR modulators. Generally, the make-up of CF MDTs had not kept pace with the changing needs of the population.

“Increasing complexity of the older patient is requiring more consultant time, which we don’t have.” Adult service (Dissatisfied)

“Pharmacy and consultant staffing [have had] no uplifts and patient numbers have doubled!” Adult service (Dissatisfied)

“After peer review it was recommended we increased [...] pharmacist [time], which has never been done. Recommendation may now be different with further increase in patient numbers and introduction of CFTR modulator therapy.” Paediatric service (Prefer not to say)

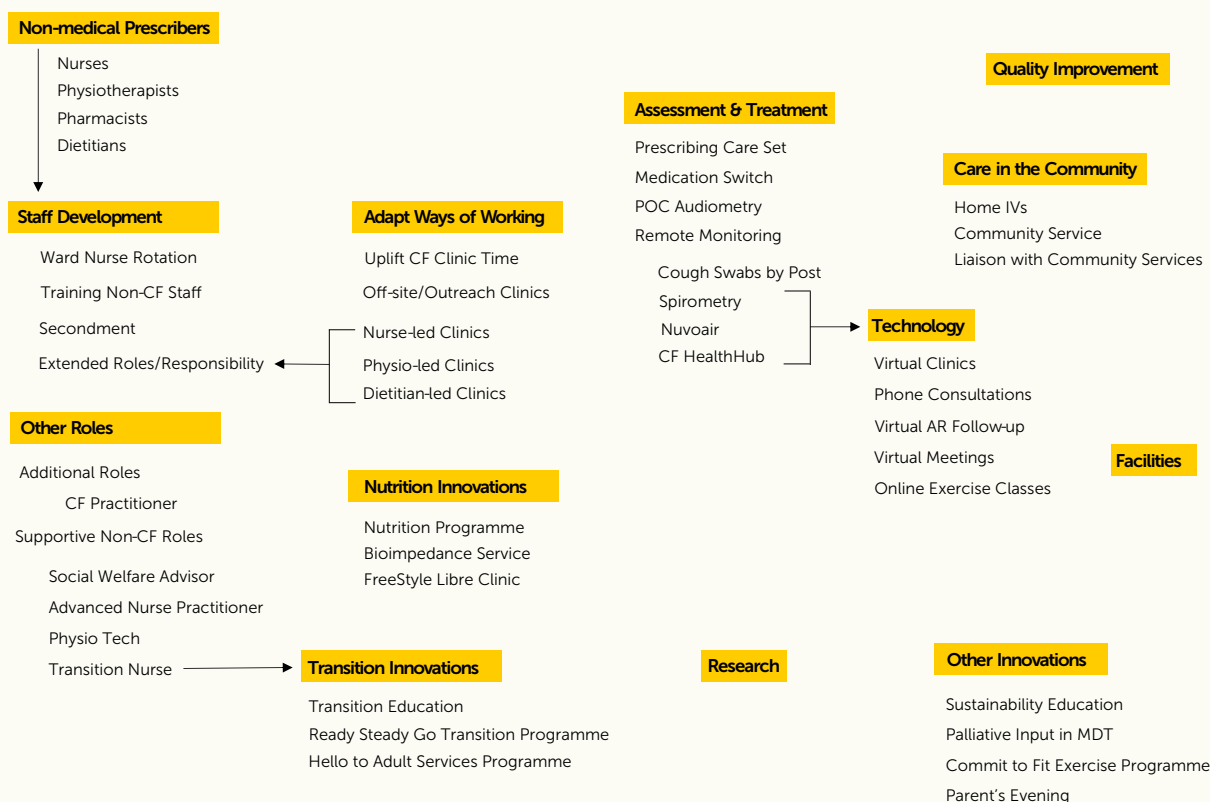
“Complex (regional) CF patients transferred to our centre requiring parenteral nutrition or neonatal care – our dietitians are not trained in these areas, so this is provided by non-CF dietetics often with daily reviews and then CF dietetics liaise with them.” Paediatric service (Dissatisfied)

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.

Service innovations

Many CF centres and teams adapt and innovate to mitigate or overcome staffing and other challenges and deliver the best possible care for people with CF. Our analysis of free text comments in the staffing tool identified a number of different approaches to addressing staff shortages and other arising challenges. Mitigating actions taken ranged from seeking additional funding for new posts and expanding existing roles, to working with technologies, other teams and community organisations to change the way care was delivered.

Figure 25: Staffing innovations and mitigations used by CF teams



Insight: CF services across the UK adapt and innovate to mitigate staffing challenges and to 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 roles and responsibilities

Developing existing members of the CF MDT plays an important part in addressing staffing challenges. In alignment with findings from previous years, many CF centres reported that they had non-medical prescribers working in their service, such as nurse, pharmacist and physiotherapist prescribers, or were training up 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 currently have three nurse prescribers with another member of the nursing team undertaking non-medical prescribing course." Paediatric service (Dissatisfied)

"The network has nurse and/or pharmacy prescribers at all three sites." Adult service (Dissatisfied)

"Physiotherapists designated to the team have completed non-medical prescribers course." Paediatric service (Prefer not to say)

Apart from non-medical prescribing, existing CF service staff also took on other additional responsibilities, and/or agreed to work extra hours, to cover staff shortages. Advanced practice roles, for example, allow physiotherapists to take bloods and carry out port flushes. Several services also mentioned that they had implemented nurse-, physio- and/or dietitian-led clinics.

"The development of the pharmacy post has improved our management of patients prescriptions, [...] improving the communication with GPs / community pharmacies." Adult service (Dissatisfied)

"[We have] advanced and non-traditional roles, for example physios trained in port flushes and bloods." Adult service (Dissatisfied)

"Database admin staff now allowed to book annual review liver ultrasounds, but doctor still has to book x-rays." Paediatric service (Satisfied)

"Nurse-led clinic." Paediatric service (Dissatisfied)

"New dietitian clinic" Adult centre (Satisfied)

Some participating centres shared that they had added new roles into the CF team to support the service, such as Advanced CF Practitioners, as well as non-CF specialist roles, such as Social Welfare Advisers, Advanced Nurse Practitioners and Physio Technicians. Non-CF specialist roles can reduce the pressure on CF specialists by taking on some of the less complex aspects of care. Other centres confirmed that they were training up non-CF staff who look after CF patients, for example through a ward nurse rotation scheme.

"Service reconfiguration includes development and recruitment of three CF Practitioners (formally CNS and Physio)." Adult service (Satisfied)

"Physio Tech and Social Welfare Advisor." Paediatric service (Satisfied)

"We now have an in-patient Advanced Nurse Practitioner for paediatric respiratory, but not specific to CF." Paediatric service (Satisfied)

"Physio team training others to help cover CF care." Adult service (Dissatisfied)

"Ward Nurse Rotation Programme – improve inpatient care for CF patients by improving nurses' knowledge of the condition, spectrum of disease and providing a global view of the CF MDT/CF Service." Paediatric service (Dissatisfied)

Changes to care delivery

Several participating services shared ways in which they had adapted how care was delivered. These included use of remote monitoring technologies and virtual or telephone consultations, as well as changes to treatments and offering more care at home and in the community.

Since the COVID pandemic, use of digital appointment formats and remote monitoring has increased significantly. Many participating CF centres confirmed that they were continuing to take a hybrid approach to delivering care, with some care done face-to-face again, but other aspects being delivered remotely. Specific remote monitoring technologies in use included home spirometry, Nuvoair and CF HealthHub. Virtual and remote care were often seen as positive and beneficial to the service, as well as its patient population.

"Virtual clinics are provided, where we prescribe modulators. We have a system for cough swabs to be sent from home, which gives us enhanced microbiology surveillance. [...] Annual reviews [are done] at hospital, however feedback and plans given virtually (save families another trip)." Paediatric service (Dissatisfied)

"Increased use of virtual platforms for some outreach workload – Teaching, Care package meetings." Paediatric service (Dissatisfied)

"We use near me technology, Nuvoair, and are flexible to the needs of patients." Paediatric service (Dissatisfied)

"70/30 virtual clinic/face-to-face clinic balance, with an increase in home visits and ad hoc face-to-face appointments." Adult service (Dissatisfied)

"[We use] home spirometry [and] CF Health Hub for measuring adherence and using the platform to upload FEV1 and weight." Adult service (Satisfied)

Other changes to care delivery mentioned by participating services included offering outreach clinics and uplifting CF clinic time.

"Specialist Centre staff provide support at the outreach clinics as well as having local staff on a permanent basis." Adult service (Dissatisfied)

"Due to reduced number of NTM [Non-tuberculous mycobacteria] patients, NTM clinics reduced to 4 times a year to implement 8 additional CF clinics a year." Adult service (Satisfied)

Care at home and in the community also plays a key role in CF care and many participating services confirmed that they were offering home visits as well as home IVs. Others said that they were working with other services in the community.

"[Planning an] increase in community service to include physio and nurse home visits once vacancies have been filled." Adult service (Dissatisfied)

"Nurse-led clinical assessment [for] home IV home-start (preventing children having to attend hospital to start IVs). [...] Offer a community service for all CF patients [and have] plans to offer online exercise/Pilates classes to CF children (physio)" Paediatric service (Prefer not to say)

"We are able to offer a home IV care service with the drugs in prefilled devices or a syringe. This helps to reduce the risk of a drug error by the parents. This has also allowed the children to spend more time at home and go back to school with IVs if clinically appropriate." Paediatric service (Prefer not to say)

"We have utilised community mental health and wellbeing services." Adult service (Dissatisfied)

"We continue to promote the Commit to Fit programme and physios linking in with local gyms and personal trainers for patients for one-to-one exercise." Paediatric service (Dissatisfied)

Finally, a few other changes to care delivery were mentioned, including implementation of prescribing care sets and changes to medications, as well as new tests/assessments, such as point-of-care audiometry.

"Introduction of a cystic fibrosis prescribing care set within the EPMA system to reduce prescribing errors. [...] Cost saving to NHS England by switching from crushed Orkambi tablets for patients unable to swallow tablets, instead of doubling up on granules" Paediatric service (Prefer not to say)

Specific, targeted innovations and mitigations

Several participating services also shared insights into targeted interventions they have implemented for specific groups of patients to address challenges they had identified. One such area was transition from children's to adult services, where a few centres had managed to introduce additional roles to support their patients.

"A new nursing role – transition nurse. To improve the transition for patients moving from the paediatric to adult service. Improve the communication between teams and support the patients on the journey into the adult service." Adult service (Dissatisfied)

"We have employed a youth worker in our team. We have developed our 'Ready Steady Go' transition programme and 'Hello to adult services' to include adherence issues and increased patient empowerment/responsibility for self-treatment in advance of adult care." Paediatric service (Dissatisfied)

With the increasing availability and use of modulators by large proportions of the CF community, centres also saw a need to focus on nutrition monitoring and education on healthy eating.

"Shortening CF dietetic reviews (would like in the future to be able to provide more education sessions to patients), providing Carbs and Cals books to patients to educate on fat content of food and manage their Creon, offering more healthy snacks to children in hospital in line with the changes in dietary requirements of CF children on modulators." Paediatric service (Dissatisfied)

"Dieticians developing Bioimpedance services. FreeLibre being used for CGM [Continued Glucose Monitoring], definitely more beneficial and convenient for patients." Paediatric service (Dissatisfied)

Other innovations used by CF centres included seeking regular input into the MDT from other specialties, such as palliative care, and offering education opportunities to people with CF and their families, including hosting parent evenings.

"A palliative care nurse and consultant in palliative medicine attend our weekly MDT meeting and see patients as needed." Adult service (Satisfied)

"[We provide] education around inhalers and sustainability." Adult service (Dissatisfied)

"Parents evenings held yearly." Paediatric service (Dissatisfied)

In addition, some services confirmed that they were actively taking part in research and clinical trials, were having regular quality improvement meetings, or had managed to improve access to inpatient facilities.

"Research involvement: CF START and CF STORM" Paediatric service (Dissatisfied)

"Weekly QI meetings to review service/systems." Adult service (Dissatisfied)

"We have finally obtained en-suite cubicle in-patient facilities for our patients." Paediatric service (Dissatisfied)

Recommendations and next steps

UK-wide recommendations

Engagement with the staffing tool has remained high despite the COVID pandemic and increasing staffing pressures across the NHS, with 43 of 60 CF centres contributing in 2022. This, together with the relatively low satisfaction levels recorded year-on-year, indicates that CF services worry about their staffing levels and are keen to review them.

Findings from our Patient-Reported Experience Measures¹⁶ show that CF teams are still delivering high quality care, but there is clear evidence that teams are stretched. The staffing tool found that CF MDTs often do not have dedicated specialist psychosocial input, nor do they consistently have access to pharmacy and research staff. 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.

High vacancy rates, particularly for CF clinical psychologists, are concerning, given the crucial role that psychosocial support plays in holistic CF care. We may also see an increasing need for this type of support in coming years due to financial pressures linked to the rising cost of living, and due to the impact of new modulator therapies on those who can and those who cannot take them. The fact that many CF services say they are struggling to recruit and/or retain qualified psychosocial staff is concerning, especially where posts remain vacant long term. In addition, several services, particularly paediatric services, said that their CF MDT did not have any funded roles in psychosocial staff groups at all.

Paediatric and adult services have different staffing configurations and face diverse staffing challenges. Consideration of service type, centre size and population needs 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 other, complementary intelligence, including data on patient experiences and outcomes, for example from the UK CF Registry.

However, from the insights provided by the staffing tool in 2022, we can make some general recommendations that apply across the UK:

- Sufficient resourcing of CF services is critical to ensure staffing levels are adequate to cater for the evolving 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 as well as NHS England's service specification is underway and may in future provide guidance on the suggested composition of CF MDTs in light of changing needs].
- 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 clinical psychology and social work.
- Continuous monitoring of staffing levels in CF centres, and across the CF population as a whole, is warranted to better understand how these change over time and to identify and explore early any trends that could impact on 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.¹⁷

16 Cystic Fibrosis Trust, Patient-Reported Experience Measures; 2022 www.cysticfibrosis.org.uk/QI

17 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. Centre 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 their staffing levels, it is important to consider the underlying causes 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 be given to the needs of a centre's population, which may also change over time and with increasing availability of CFTR modulators. This could be facilitated by regularly capturing and reviewing patient outcomes and experiences, for instance through ongoing contribution to Cystic Fibrosis Trust's CF 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, alongside 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 and others 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 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 life fulfilled.

The staffing tool shows that not all people with CF consistently have access to a full specialist MDT, and that staff time is also limited, particularly for psychosocial staff groups. CF teams 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 seek 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 to develop business cases based on data insights. Depending on the specific challenges a service is experiencing, existing resources and support offers from Cystic Fibrosis Trust will also be relevant and helpful. We will also consider further actions as a result of the issues identified in this report.

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 the tool and will encourage all CF centres across the UK to participate to give as clear a picture as possible of CF staffing levels and any changes over time.

The QI team can be contacted at: QI@cysticfibrosis.org.uk

Glossary

Word/phrase	Meaning
Centre	Hospital providing expert care and specialised disease management to people living with cystic fibrosis
CF	Cystic Fibrosis
CFTR modulators	CFTR modulators and modulator therapies, also known as 'precision medicines', work to tackle the underlying cause of cystic fibrosis (i.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 is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

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

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